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Executive summary

Introduction

This report presents the results of the first evaluation of the Alberta Prion Research Institute. The Prion Institute provides financial support for research capacity building, research and development projects including funding of facilities and equipment, and knowledge mobilization activities in the fields of prion diseases and other neurological diseases with prion-like characteristics. A total of $46.7 million were invested in research projects, infrastructure and personnel support through the Prion Institute between its creation in April 2005 and August 2015.

This summative evaluation, conducted in 2015/16, focused on identifying successes, impacts and challenges associated with the delivery of the Prion Institute’s research funding programs for the duration of its existence. The evaluation was commissioned by the Prion Institute in accordance with the reporting requirements of the 2012–2015 funding agreement between the Ministry of Innovation and Advanced Education and AI Bio. The findings and recommendations contained in this report will contribute to inform strategic planning and decision-making for the Prion Institute going forward.

Science-Metrix was responsible for carrying out an external and independent evaluation, while the Prion Institute and AI Bio provided advice and oversight. A mix of quantitative and qualitative data were collected through five evaluation methods, including a document and literature review, a bibliometric analysis, semi-structured interviews and a survey of funded researchers. The key evaluation findings and key considerations are summarized below.

Methodologies

Given the summative nature of the evaluation, the focus was on assessing the extent to which the three expected outcomes have been met. The evaluation also addressed a number of process-oriented questions of interest to the Prion Institute. A combination of qualitative and quantitative methods were employed. The Evaluation Framework that guided the data collection is located in Appendix A.

There were five data collection methodologies employed altogether:

- Documentation and literature review;
- Bibliometric analysis;
- Interviews;
- E-survey; and
- Case studies.

The methodologies were each purposefully chosen to fit the nature of the data to be collected and the composition of the data sources, including the individuals to be interviewed or surveyed.

The qualitative data gathered through interviews, whether as part of the interviews methodology or the case studies methodology, were validated only insofar as complementary lines of inquiry provided similar evidence. All findings presented herein are supported by the collective evidence; however, not all statements obtained during the data collection process could be confirmed. As such, the findings supported primarily by interview data are based on real or perceived situations.
Constraints and Limitations

The evaluation budget and timelines allowed for a particular number of interviews to be scheduled and conducted within a relatively short period of time. Although the target number of interviews was met overall, the level of coverage within certain interviewee categories is minimal due to a lack of availability to participate for some interviewees. Consequently the findings are limited in some cases and should be interpreted accordingly. Those individuals with extensive, long-standing involvement and/or knowledge of the Prion Institute and its history were categorized as “key informants”, and their responses were weighted more heavily in the analysis of interview data.

Key findings – Outcome 1: Strong Alberta capacity for prion and prion misfolding science

The Prion Institute was found to be the primary contributor to the increase in capacity of prion and protein misfolding science in Alberta, which is reflected by a meaningful growth in peer-review publications in the field over the period 2005–2014. This growth was driven by the large infrastructure investments made and leveraged by the Prion Institute for the development of core prion-dedicated facilities and equipment at Alberta’s two main universities, which were instrumental in the recruitment of 11 world-renowned prion and protein misfolding researchers to Alberta institutions. These researchers, their direct collaborators, trainees and research staff constitute the core research pool of Alberta in both animal and human prion-related research, a pool that is further strengthened by the numerous collaborations developed with Canadian researchers outside of Alberta with the support of the Prion Institute. The Prion Institute was also found to have put in place the funding and training mechanisms and opportunities for researchers to adequately train and mentor the next generation of prion and protein misfolding scientists (the HQP) in Alberta and Canada.

Key findings – Outcome 2: Knowledge generation in fundamental and applied areas that leads to prevention, mitigation and treatment of prion and protein misfolding diseases in animals and humans

Alberta has become more specialized in prion and protein misfolding research over time. Moreover, citation impact was maintained in the early years of the Prion Institute, and recently has shown growth in citation impact despite increases in output of publications during its time of existence. Bibliometric analyses showed some encouraging trends in the average relative impact of funded peer-review publications over the last few years, and it is expected that with the completion of new prion facilities, researchers will start publishing an increasing number of high-impact publications.

Prion Institute funded research has not yet translated into many therapeutic, industry or policy applications to prevent, mitigate and treat prion and protein misfolding diseases. This is likely a factor of the long-term and complex nature of prion and protein misfolding research and translational research in general. Evidence also indicates that the Prion Institute’s focus on developing a strong basic knowledge base might have outweighed its support for translational research. Despite this finding, promising applications are underway, including the development of both SRM-related technologies and vaccines for CWD.
Key findings – Outcome 3: Mobilization of knowledge generated for use by industry, government and researchers

The Prion Institute’s strong leadership in building partnerships, knowledge transfer and exchange activities provided significant value to researchers and policymakers. Of particular note is the organization of the international PRION 2011 (its first year in Canada), PRION 2013 (widely regarded as the best of the annual conferences), the SRM international discussion that was held in 2015, and regular discussions with provincial government representatives. Evidence shows that industry stakeholders are less engaged in Prion Institute events today than during the period shortly after the creation of the Prion Institute, in the wake of the BSE crisis.

The Prion Institute also developed key partnerships over the years, with PrioNet and later with the Alberta Livestock and Meat Agency and the Alberta Alzheimer Research Program co-funded by the Alzheimer Society of Alberta & Northwest Territories.

Stakeholders generally found the Prion Institute’s communication and public awareness activities to be of good quality and useful. Jay Ingram’s lectures were considered a powerful tool to educate rural communities about the latest advances in prion and protein misfolding research, although options could be explored to reach a wider audience. Communication products, such as the public annual report, the website and knowledge outreach related materials were all deemed well designed and informative.

Key findings – Relevance and efficiency

The grant programs offered by the Prion Institute were deemed relevant and adequate and stakeholders did not identify any major gaps, although there is a perception that the Prion Institute is focusing less on livestock industry oriented research. It is unknown whether or not those holding this perception believe this lesser focus is deliberate.

The Prion Institute is generally effective in its program delivery and management practices. The Prion Institute’s position as an institution at arm’s length from government was perceived as a key contributor to the successful delivery of its activities. Overall, internal and project-level reporting requirements are adequate, aside from timeliness issues with reporting to the government and working with some partners. At the project level, researchers lauded the recent decision to move to annual reporting. The data point to the possibility that the reporting timeliness issues as well as issues related to the capturing and monitoring of financial information might be a consequence of a lack of human resources.

Key considerations for future operations

The following key considerations, stemming from the evaluation findings, are intended to assist the Prion Institute in further improving the efficiency of its program delivery and ensuring continued relevance of its activities to its stakeholders.

1. The Prion Institute, in light of real or perceived industry disengagement, should review its mandate with an eye toward the nature of the research it will continue to fund, and whether this aligns with the overarching objectives of the organization.
2. The Prion Institute should clarify messaging in two areas: (1) the nature of the research projects that are eligible for funding under the different grant offerings made available to researchers; and (2) the potential value the stakeholder community can expect from the funded research.

3. The Prion Institute should regularly undertake a workload assessment process to ensure staffing levels are adequate to meet demands more efficiently.

4. Additional efforts should be made by the Prion Institute to collect impact data at, or following, knowledge transfer and community outreach activities.
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### Abbreviations, acronyms and initialisms

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<th>Abbreviation</th>
<th>Full Form</th>
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<tbody>
<tr>
<td>ADM</td>
<td>Assistant Deputy Minister</td>
</tr>
<tr>
<td>AI Bio</td>
<td>Alberta Innovates Bio Solutions</td>
</tr>
<tr>
<td>ALMA</td>
<td>Alberta Livestock and Meat Agency</td>
</tr>
<tr>
<td>ARC</td>
<td>Average of relative citations</td>
</tr>
<tr>
<td>ASRIP</td>
<td>Alberta Science and Research Investments Program</td>
</tr>
<tr>
<td>ARIF</td>
<td>Average of relative impact factors</td>
</tr>
<tr>
<td>BSE</td>
<td>Bovine spongiform encephalopathy</td>
</tr>
<tr>
<td>CEO</td>
<td>Chief Executive Officer</td>
</tr>
<tr>
<td>CFI</td>
<td>Canada Foundation for Innovation</td>
</tr>
<tr>
<td>CFIA</td>
<td>Canadian Food Inspection Agency</td>
</tr>
<tr>
<td>CIHR</td>
<td>Canadian Institutes of Health Research</td>
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<tr>
<td>CPPFD</td>
<td>Centre for Prions and Protein Folding Diseases</td>
</tr>
<tr>
<td>CWD</td>
<td>Chronic wasting disease</td>
</tr>
<tr>
<td>DNA</td>
<td>Deoxyribonucleic acid</td>
</tr>
<tr>
<td>HCPs</td>
<td>Highly Cited Publications</td>
</tr>
<tr>
<td>HQP</td>
<td>Highly-qualified personnel</td>
</tr>
<tr>
<td>IRAC</td>
<td>International Research Advisory Council</td>
</tr>
<tr>
<td>MLA</td>
<td>Member of the Legislative Assembly</td>
</tr>
<tr>
<td>NSERC</td>
<td>Natural Sciences and Engineering Research Council</td>
</tr>
<tr>
<td>PHAC</td>
<td>Public Health Agency of Canada</td>
</tr>
<tr>
<td>PI</td>
<td>Principal investigator</td>
</tr>
<tr>
<td>RNA</td>
<td>Ribonucleic acid</td>
</tr>
<tr>
<td>SI</td>
<td>Specialization index</td>
</tr>
<tr>
<td>SRM</td>
<td>Specified Risk Material</td>
</tr>
<tr>
<td>TSE</td>
<td>Transmissible spongiform encephalopathy</td>
</tr>
<tr>
<td>UK</td>
<td>United Kingdom</td>
</tr>
<tr>
<td>US</td>
<td>United States</td>
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</tbody>
</table>
1 Introduction

1.1 About the Alberta Prion Research Institute

The Alberta Prion Research Institute (Prion Institute) was created in 2005 in response to the 2003 bovine spongiform encephalopathy (BSE) crisis, which estimates suggest resulted in economic losses in the billions of dollars.¹ As Canada’s primary beef-producing province, Alberta was particularly hard-hit by the incident; the Government of Alberta made a decision to invest in research to better understand BSE and other prion and prion-like diseases in order to mitigate the risks of major negative economic and social impacts in the future and to build research capacity in the province.

While BSE is among the better-known prion diseases amongst the general population, there are many prion and prion-like diseases that affect animals and humans. A prion is a misfolded form of a normal protein that causes infectious disease of the nervous system. Unlike viruses and bacteria, prions do not require DNA or RNA to replicate and cause disease.

Prion diseases result in a sponge-like degeneration of brain tissue, and ultimately the death of the affected human or animal. They are transmissible from one individual to another from the same species, as well as across species in the case of BSE. The following are some examples of prion diseases and the mammals they affect:

- Bovine spongiform encephalopathy (BSE; cattle, bison, buffalo);
- Chronic wasting disease (deer, elk and moose);
- Creutzfeldt-Jakob disease (humans);
- Fatal familial insomnia (inherited disease of humans);
- Feline spongiform encephalopathy (domestic and captive felines, possibly caused by consumption of BSE-contaminated meat);
- Gerstmann-Sträussler-Scheinker disease (inherited disease of humans);
- Scrapie (sheep and goats); and
- Variant Creutzfeldt-Jakob disease (humans, acquired from eating beef from cattle infected with BSE).

The Prion Institute provides financial support for research capacity building, research and development projects including funding of facilities and equipment, and knowledge mobilization activities in the fields of prion diseases and other neurological diseases with prion-like characteristics.² Based on internal financial documentation, the Government of Alberta has invested $46.7 million in research projects, infrastructure and personnel support through the Prion Institute between its creation in April 2005 and August 2015.

1.1.1 Governance

The governance structure of the Prion Institute has evolved over time. At its inception, the Prion Institute was part of Alberta Ingenuity (Ingenuity) from 2005 to 2010. While a part of Ingenuity, the Prion Institute was governed by a Management Board with a responsibility to set the strategic plan, including the
communications plan, risk management parameters and procedures, the program structure and reporting requirements. The Management Board reported to the CEO of Ingenuity, who reported directly to the Ingenuity Board of Trustees.

Since 1 January 2010, Alberta Innovates Bio Solutions (AI Bio) has been the parent agency of the Prion Institute. Its Executive Director reports to the Chief Executive Officer (CEO) of AI Bio, who in turn reports to the AI Bio Board of Directors. AI Bio originally administered the Prion Institute’s contract through the Ministry of Innovation and Advanced Education. In October 2015, the Government of Alberta announced the creation of the new Ministry of Economic Development and Trade, into which AI Bio and other Alberta Innovates organizations were subsumed. The current contract is a five-year contract awarded by the Government of Alberta and runs through to 31 March 2020. The previous contracts were a seven-year contract (2005–2012) and a three-year contract (2012–2015). The Prion Institute has two major advisory bodies, characterized as follows:

- **The International Research Advisory Council (IRAC)** – Comprising five to eight international experts in fields related to prion and protein misfolding disease research, the IRAC reviews grant applications and provides scientific advice and funding recommendations to Prion Institute staff.
- **The College of Reviewers** – This group provides expert external peer review of grant applications submitted to the Prion Institute.

### 1.1.2 Expected outcomes

The Prion Institute established a set of 10 outcomes at its inception in 2005. These outcomes have changed over time, primarily in 2012 to coincide with the establishment of the Institute’s second funding agreement with the Government of Alberta. Currently there are three expected outcomes for the Prion Institute, but the 10 originally-established outcomes align with the themes of the current outcomes. Table 1 illustrates the alignment between the 2005 outcomes and 2012 outcomes.

The outcomes of the Prion Institute cover three thematic areas:

1. Capacity-building
2. Knowledge generation
3. Knowledge transfer, exchange and translation
### 1.2 About the summative evaluation

This summative evaluation was carried out as part of the reporting requirements of the Prion Institute, in accordance with the 2012–2015 funding agreement between the Ministry of Innovation and Advanced Education and AI Bio. The focus of the evaluation was to identify successes, impacts and challenges associated with the delivery of the Prion Institute’s research funding programs for the duration of its existence between 2005 and 2015. This was the first such evaluation of the Prion Institute carried out to date. The Prion Institute regularly collects performance data against its programming for use in annual reporting; however, such output data has limitations with respect to planning. As such, this evaluation report and the findings and recommendations contained herein will be an important tool to inform strategic planning and decision-making for the Prion Institute going forward.
2 Methodologies

Given the summative nature of the evaluation, the focus was on assessing the extent to which the three expected outcomes have been met. The evaluation also addressed a number of process-oriented questions of interest to the Prion Institute. A combination of qualitative and quantitative methods were employed. The Evaluation Framework that guided the data collection is located in Appendix A.

There were five data collection methodologies employed altogether:

- Documentation and literature review;
- Bibliometric analysis;
- Interviews;
- E-survey; and
- Case studies.

The methodologies were each purposefully chosen to fit the nature of the data to be collected and the composition of the data sources, including the individuals to be interviewed or surveyed.

2.1 Document and literature review

A documentation review was undertaken to position the Prion Institute within the prion research and organizational context to identify enabling factors and barriers to performance. The aim of the document review was to help solidify the understanding of the Prion Institute, and to make use of existing performance reports and data as an input into the evaluation.

Close to 200 documents relating to the Prion Institute and/or its programming were provided by the Director, Prion Programs. The complete list is located in Appendix B. All of the documents were initially assessed to determine their relevance or usefulness to the evaluation. Those deemed useful were reviewed in detail against the evaluation indicators (see Evaluation Framework in Appendix A).

The documentation reviewed included, but was not limited to, the following:

- Prion Institute annual reports;
- Prion Institute funding agreements;
- lists of funded researchers and projects;
- program description documents; and
- financial documentation.

A literature review was also carried out in a limited fashion as a means to explore the program delivery mechanisms employed by other similar research funding institutions around the world. The literature review was initialized by attempting to identify similar organizations, then attempting to determine their foci of study and their methods of funding researchers. Through this process we identified several organizations that were either funding agencies or research institutions specifically (e.g., the Medical Research Council Prion Unit, PrioNet Canada, NeuroPrion, the National Prion Disease Pathology Surveillance Center). The evaluation then relied on incoming interview data to further broaden the search by honing in on countries with a particular interest in prion research or BSE research in particular. The purpose was to determine if there were any such institutions that funded prion research specifically.
It was determined that there were no prion research funding organizations with a similar mandate. The focus of the search was then further broadened to explore general research funding organizations, such as Genome Canada, the Natural Sciences and Engineering Research Council (NSERC) and the Canadian Institutes of Health Research (CIHR). Ultimately, the literature review, given its intended purpose, did not provide significant value to the evaluation; however, some interesting discoveries have been incorporated where appropriate.

### 2.2 Bibliometric analysis

A bibliometric analysis was conducted to assess the influence of the Prion Institute on the scientific production and citation impact of Alberta publications related to research on prion and prion-like diseases, the structure of the prion protein and possible functions of the prion protein. The scientific performance of Alberta and Alberta research institutions was also examined in comparison to that of other provinces and top publishing countries in the field, for the pre- and post-Prion Institute periods. The bibliometric analysis also identified the position of Prion Institute-funded researchers within the Canadian and international research communities active in this field. Given that there was very limited scientific output (less than five publications annually) related to prion and protein misfolding research in Alberta prior to the inception of the Prion Institute, bibliometric indicators for the whole province were used as a proxy for assessing the impact of the Institute.

For this study, five indicators were used to assess the performance of the Prion Institute-funded researchers, Canada, Canadian organizations, Canadian researchers and top publishing countries:

- Number of papers;
- Average of relative citations (ARC);
- Average of relative impact factors (ARIF);
- Highly Cited Publications (HCPs); and
- Specialization index (SI).

Brief descriptions of each of these indicators as well additional details on the bibliometric analysis are provided in Appendix C.

### 2.3 Interviews

Interviews were conducted by telephone or in person with 42 internal staff, external partners, researchers and other stakeholders familiar with the Prion Institute, its processes and mandate. The breakdown of representation is shown in Table 2.

Note that the table also indicates the number within each category considered to be “key informants.”
Table 2 Interview distribution

<table>
<thead>
<tr>
<th>Category of interviewee</th>
<th>Number interviewed</th>
<th>Number of key informants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Academia</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Historical perspective</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Industry</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>International Review Advisory Council</td>
<td>2</td>
<td>-</td>
</tr>
<tr>
<td>Partners</td>
<td>11</td>
<td>1</td>
</tr>
<tr>
<td>Program management / staff</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>Researchers</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>Senior management (including Alberta Innovates Bio Solutions)</td>
<td>3</td>
<td>-</td>
</tr>
<tr>
<td>Students</td>
<td>4</td>
<td>-</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>42</strong></td>
<td><strong>7</strong></td>
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The purpose of the interviews was to obtain a variety of perspectives on the efficiency of program implementation, including the selection of funding recipients and any ongoing monitoring of their activities, as well as on some of the key successes and challenges experienced over the Prion Institute’s 10-year history. In addition, the interviews provided insights into the successes and the nature of impacts resulting from research activities. Interviews were recorded, transcribed and analyzed in Atlas.ti using a system of closed and open coding. Recordings were destroyed following the transcription process.

Tailored interview guides were developed for each category of stakeholder. A conversational approach was taken with the interviews, so that certain topics could be explored in depth with individuals particularly knowledgeable in certain areas. The master interview guide is located in Appendix D.

2.4 E-survey

An e-survey targeting funded researchers was implemented to gather perspectives on the Prion Institute’s policies, programs and management. Given the relatively small population of funded researchers (n=48), almost all researchers who have been funded through the Prion Institute were invited to participate in the survey.

The relatively small population also meant that a response rate of 92% would have been required to ensure statistical reliability. There was not a realistic likelihood that this would occur, so the evaluation set a target response rate of 66.7% (n=32). The evaluation came up short by the narrowest of margins, resulting in a 65% (n=31) response rate. The survey findings have been treated as indicative of only the
31 researchers who responded because even at 95% confidence the margin of error (±11%) was too large to generalize for the entire population of researchers.

The survey questionnaire (see Appendix E) was developed and tested internally by the evaluation team members. Once validated internally, the survey was then externally pre-tested with representatives of the Prion Institute. Lastly, after invitations were sent to researchers, the first two responses were reviewed in detail to confirm the questionnaire was clear and valid. No adjustments were needed following this pre-test.

The e-survey invitations were sent to potential respondents by email through the Fluid Survey platform. Respondents had access to the e-survey through a unique link, which permitted tracking of respondents in real time. The survey was made available from 13 October 2015 until 27 October 2015. Researchers had this two-week period to respond to the survey. Two reminders were sent during this period.

Quantitative data analysis was performed using Excel to prepare pivot tables for cross-tabs analyses. Qualitative data, albeit largely limited, was also analyzed in Excel using open-ended coding.

2.5 Case studies

Five case studies were conducted as a means to demonstrate the Prion Institute’s theory of change. A thematic case study approach was implemented, which focused on the outcome themes presented in section 1.1.2. The case studies documented activities and outcomes associated with the theme they represented. The cases provided evidence of the effect of activities in making an impact on researchers and other stakeholders implicated by the activities.

Case studies were conducted in the following areas:

- Building Capacity in Prion Science (Infrastructure funding at the universities of Alberta and Calgary);
- Highly-Qualified Personnel (Individuals involved in recruitment/researcher training);
- Outreach (Public lectures);
- Partnership Leveraging (PrioNet Canada); and
- Innovations (Plastic made from Specified Risk Material).

The selection criteria used to select the cases were

- the outcome theme to which the case relates;
- the extent that the case aligns to multiple outcome themes;
- the program under which the funding was received; and
- the magnitude of the funding received.

Each case study involved a review of related documents and files, which in some instances included project applications/proposals, funding agreements, interim/final project reports, scientific publications (e.g., technical, scientific, or regulatory in nature) and financial information. Additionally, a maximum of three interviews were conducted per case. In some instances information collected through the interviews methodology was useful to the development of case studies, and as such that information was incorporated where appropriate into the case studies.
Five brief stand-alone documents were produced as a result of the case studies using a case study template. These documents are provided in Appendix F.

2.6 Constraints and limitations

The qualitative data gathered through interviews, whether as part of the interviews methodology or the case studies methodology, were validated only insofar as complementary lines of inquiry provided similar evidence. All findings presented herein are supported by the collective evidence; however, not all statements obtained during the data collection process could be confirmed. As such, the findings supported primarily by interview data are based on real or perceived situations.

Furthermore, the evaluation budget and timelines allowed for a particular number of interviews to be scheduled and conducted within a relatively short period of time. Although the target number of interviews was met overall, the level of coverage within certain interviewee categories is minimal due to a lack of availability to participate for some interviewees. Consequently the findings are limited in some cases and should be interpreted accordingly. Those individuals with extensive, long-standing involvement and/or knowledge of the Prion Institute and its history were categorized as “key informants”, and their responses were weighted more heavily in the analysis of interview data.

Regarding the e-survey, as noted previously, the survey sample was not large enough to allow for the generalization of findings to all researchers with 95% confidence and a reasonable margin of error. As such, the findings apply only to the 31 respondents, and do not provide information about the 17 non-respondents. Despite this limitation, given that the survey results demonstrated a very high degree of consistency, it is unlikely, even with the current margin of error of ±11%, that there would be a difference in these survey results with a lower margin of error.
3 Findings

3.1 Outcome 1: Strong Alberta capacity for prion and protein misfolding science

Q1 – To what extent has the Institute contributed to capacity for prion and protein misfolding science in Alberta?

Q2 – To what extent has the Institute had an effect on the development and support of core research infrastructure in Alberta?

Q3 – To what extent, and by what means, has the Institute contributed to the development of highly qualified personnel?

Q4 – To what extent has the Institute been able to influence the recruitment of new faculty members to Alberta institutions?

The Prion Institute was found to be the primary contributor to the increase in capacity of prion and protein misfolding science in Alberta, which is reflected by a meaningful growth in peer-review publications in the field over the period 2005–2014. This growth was driven by the large infrastructure investments made and leveraged by the Prion Institute for the development of core prion-dedicated facilities and equipment at Alberta’s two main universities, which were instrumental in the recruitment of 11 world-renowned prion and protein misfolding researchers to Alberta institutions. These researchers, their direct collaborators, trainees and research staff constitute the core research pool of Alberta in both animal and human prion-related research, a pool that is further strengthened by the numerous collaborations developed with Canadian researchers outside of Alberta with the support of the Prion Institute. The Prion Institute was also found to have put in place the mechanisms and opportunities for researchers to adequately train and mentor the next generation of prion and protein misfolding scientists (the HQP) in Alberta and Canada.

The Prion Institute has contributed to the Albertan and Canadian scientific production in prion and protein misfolding science.

The evaluation found that the capacity for prion and protein misfolding science has increased significantly in Alberta, and correlatively in Canada, over the period 2005–2015, primarily as a result of the Prion Institute’s leadership and funding support. To quote an interviewee:

Basically we went from 0 to 100; we had no one here in Alberta or very few people doing this type of research. It really can’t be overstated the influence [the Prion Institute] has had: without them and somebody with a vision of the fact that people in other parts of the world had the expertise and that they needed to bring them in and build the infrastructure, we would not be where we are now.

This capacity increase is reflected by the substantial growth in scientific production of peer-reviewed publications in Alberta from the period prior to the creation of the Prion Institute to the subsequent period. The total number of peer-reviewed papers produced went from 15 between 1996 and 2004 to 233 between 2006 and 2014. Canada has the third highest output growth rate among the top 20 countries.
in prion and protein misfolding research (3.88 times the world average growth), which was largely driven by the rapid increases in Alberta-based research output, as shown in Figure 1.

Figure 1  Trend in publication output of Alberta and share of world publication output in prion and prion misfolding research between 1996 and 2014

The Alberta scientific production in the prion and protein misfolding field represents on average 36% of the Canadian output and 3% of the global output since 2006, compared to 11% and 0.2% respectively for the period preceding the inception of the Prion Institute. Alberta currently produces at least four times more prion publications (Specialization Index of 4.2) than would be expected given its share of the world scientific production across all research fields, which makes it the most specialized province in Canada in prion and protein misfolding research. Moreover, since 2011, Alberta has been surpassing Ontario in the share of Canadian scientific output, thus positioning Alberta as the focal point for the production of prion and protein misfolding research in Canada (Figure 2).
Infrastructure investments were a key driver in the recruitment of high-calibre researchers.

Evidence from the interviews, survey and case studies indicates that the positive publication production outcomes for Alberta resulted directly from major prion infrastructure developments, key recruitments, and dedicated and sustained prion research funding, all made possible through the combined efforts of the Prion Institute and its partners at the national and provincial levels. In particular, the substantial investments made by the Prion Institute to build and equip state-of-the-art facilities dedicated to prion research in Edmonton and Calgary were instrumental in attracting and retaining 11 world-renowned prion and protein misfolding researchers to Alberta.

According to interviewees, without such facilities, the province would likely not have been able to recruit scientists of such high calibre as they were for the most part already well established in their previous labs. The availability of lab facilities was, on average, the second factor that had the most influence on survey respondents’ decision to relocate to Alberta (ranked at 2.7 on a 1 to 7 influence scale), after the availability of research funding (1.7). Overall, almost half (46%) of the researchers responding to the survey and 60% of those who relocated to Alberta indicated they would not have chosen to conduct prion research in Alberta in the absence of Prion Institute funding.

The most striking example of infrastructure development was the creation of the University of Alberta’s Centre for Prions and Protein Folding Diseases (CPPFD) in 2006. Internal documents indicate that the Prion Institute awarded a total of $2 million to Dr. David Westaway at the University of Alberta to cover equipment acquisition and infrastructure costs related to the renovations of the building used to host the CPPFD. The University of Alberta contributed $820,000 for the planning, design and engineering consultancy. Dr. Westaway leveraged Prion Institute funding to secure a total of $22.9 million in contributions from other sources, including the Canada Foundation for Innovation (CFI), the Alberta Science and Research Investments Program (ASRIP – another Government of Alberta source of funding for research), the Natural Sciences and Engineering Research Council (NSERC) and the University of Alberta.
The main objective of these investments was to build level 2 or level 2+ biosafety level containment facilities, including small animal facilities, and equip them with cutting edge prion research lab equipment, according to internal documents. Such biosafety levels allow researchers to conduct lab research with infectious prion materials in a safe environment; few labs in Canada and the world were said to have such large and well-equipped areas of lab space and animal facilities within such high levels of biosafety containment. Interview evidence strongly suggests that Dr. Westaway, one of the most notable prion researchers in the world, relocated to Edmonton because he was given the unique opportunity to build a prion centre from the ground up: one where he could have access to high-powered instrumentation that several competitors did not have and where all the equipment and facilities were centralized and not distributed through several buildings across the campus, as was the case in his previous lab at the University of Toronto. Several other key prion and protein misfolding researchers joined the lab over the years for similar reasons, including Dr. Valerie Sim, Dr. Judd Aiken, Dr. Debbie McKenzie and Dr. Holger Wille.

The University of Calgary also benefited from the Prion Institute’s support in developing the Calgary Prion Research Unit within the Health Research Innovation Centre. Internal documents show that while the university made some initial investments in 2005–06, the major infrastructure developments officially started around 2009, when Dr. Stefanie Czub and a few other researchers secured $1.9 million from the Prion Institute. This was for the acquisition of equipment to be used in the shared laboratory for processing and analysis of specimens containing infectious prions, as well as equipment for associated offices. The funding was also used to cover 50% of the costs for the construction of an animal facility. The remaining 50% was funded by the CFI and the University of Calgary. Some additional lab space for other recruits was also built, although without the Prion Institute’s support. The facility received the Canadian Food Inspection Agency (CFIA) and Public Health Agency of Canada (PHAC) biosafety level 2+ containment certification in 2013–14. The Prion Institute’s investments successfully leveraged $2.3 million from the CFI, the Canadian Institutes of Health Research and the University of Calgary.6

Interviewees explained that, unlike Dr. Westaway at the University of Alberta, Dr. Czub and the other researchers who initiated the development of new prion facilities in Calgary had other roles to focus on and were not solely committed to securing funding for a new facility at the University of Calgary. In 2013, the University of Calgary was able to attract two high-calibre researchers, Hermann Schätzl and Sabine Gilch, dedicated to the unit. Interview evidence strongly indicates that these two key researchers and others who joined the unit over the years would not have relocated to Alberta without the assurance that they would be in charge of running fully equipped, state-of-the-art prion research dedicated containment facilities.

Lastly, through the SRM-CAP Specified Risk Material Program, the Prion Institute made additional capital investments totalling $1.5 million to facilitate SRM research being conducted by a few of the funded researchers. These investments supported facility rentals, renovations, laboratory supplies and major specialized equipment.

The funded facilities are world calibre.

Interview and survey evidence indicates that the Prion Institute-funded prion facilities compare well with other facilities in Canada and the world. Interviewees indicated that the new prion units allowed
researchers, especially those at the CPPFD, to compete with the best prion and prion-like disease researchers in the world; only a few other labs in the US and UK were said to be slightly better equipped and funded, notably because they benefit from higher levels of philanthropic and public funding support respectively. Interviewees also noted that a flow-on effect of the provision of this equipment and these techniques in the field is that it contributes to building a pool of HQP because undergraduate and graduate students have direct access to them, and some of these students may choose to pursue prion or prion-related research in the future.

Further evidence is derived from the survey in which two-thirds of survey respondents (65%) reported that the lab facilities available to them for their Prion Institute-funded research were better (26%) or significantly better (39%) than the lab facilities at institutions outside of Alberta (Figure 3).

**Figure 3** How do the lab facilities available to you for your Prion Institute-funded research compare with the lab facilities you are familiar with at institutions outside of Alberta?

![Lab facilities comparison chart](chart.png)

Source: Alberta Prion Research Institute. Survey of Prion Institute-funded researchers, 2015

Key informants from both the CPPFD and the Calgary Prion Research Unit did mention delays associated with setting up the new units and difficulties in securing operational funding from provincial and national sources to cover lab management and animal caretaking related costs. A key informant noted that the CPPFD has had difficulties negotiating funding to cover the costs associated with service contracts for the maintenance of research equipment, which are typically very expensive. This issue has been recognized and is now being addressed, notably through the Prion Institute’s implementation of an operational fund that will allow the two groups to share an annual fund to cover new equipment, service contracts and staffing.

**There is greater integration of Prion Institute-funded researchers across the country.**

Alberta’s capacity in prion and protein misfolding research is also linked to the availability of and access to relevant expertise outside of its core research pool, reflected by the level of collaborations between Prion Institute-funded researchers and other Canadian researchers. As shown in Figure 4 and Figure 5, the Prion Institute’s funded researchers have been more integrated across the country since the Prion...
Institute was created in 2005. Somewhat converse views were expressed by interviewees, who felt that most of their research collaborations were with researchers funded by the Prion Institute, or with researchers with whom they had been working prior to receiving the Prion Institute’s support. Interview evidence also suggests that the level of collaborations with Canadian researchers outside the province has decreased since the dissolution of PrioNet, which previously funded such researchers, because some researchers outside of Alberta have left the prion field due to lack of funding from other Canadian sources.
Figure 4  Network collaboration between Canadian researchers in prion and protein misfolding research (1996–2004)

Note: The size of the nodes is proportional to the number of publications and the width of the links is proportional to the number of co-publications between researchers in the network. Prion Institute-funded researchers are coloured in blue in the network.

Source: Computed by Science-Metrix using the Web of Science™ (Thomson Reuters)
Figure 5  Network of collaboration between Canadian researchers in prion and protein misfolding research (2006-2014)

Note: The size of the nodes is proportional to the number of publications and the width of the links is proportional to the number of co-publications between researchers in the network. Prion Institute-funded researchers are coloured in blue in the network.

Source: Computed by Science-Metrix using the Web of Science™ (Thomson Reuters)


Training and career development activities are contributing to producing highly qualified personnel.

The Prion Institute does not provide salary support in the form of scholarships and fellowships directly to young researchers; however, more than two-thirds of the grant money it provides is used to pay the salaries of graduate students, postdoctoral fellows, lab technicians and research associates. The evaluation found that the Prion Institute has also contributed to the training of young research professionals, mainly through the provision of funding for travel to networking activities, participation in ongoing research projects and career enrichment opportunities. These activities were said to contribute to developing the next generation of researchers in prion and protein misfolding research.

Overall, the Prion Institute’s 2014–15 annual report indicates that between 2005 and 2015:

- a total of 370 young research trainees and research assistants were supported and trained by the Prion Institute; and
- 177 students and fellows have taken advantage of career enrichment opportunities provided through the Prion Institute and its partners.

Some of the key HQP training mechanisms and opportunities identified through the interviews, case studies and documentation included the following:

- Additional direct funding support for travel to the national PrP CANADA and international PRION conferences; for example, 13 young researchers received a total of $15,750 to attend PRION 2014 in Italy, 27 trainees received a total of $16,000 in travel support to attend PRION 2013 conference in Banff, and approximately 100 HQP went to the 2010 PrP CANADA in Ottawa. The remaining costs of their travel were covered through principal investigators’ grants.
- Participation in funded research projects (with salary support from the Institute’s grants) where HQP are actively involved in the design and execution of experiments and the writing of scientific publications.
- Professional development opportunities through the Expanding Horizons Program and workshops held during the national PrP CANADA conferences and PRION 2013 to help HQP broaden their hard and soft skills outside of the lab; for example, 60 trainees participated in the Expanding Horizons Program to gain skills related to grants crafting, careers in industry, interview skills and media training.

Interviewees’ responses showed that the Prion Institute’s supported activities have had a positive impact on HQP’s research production and quality, scientific collaborations, professional development and career advancement. Most notably, HQP were said to have gained strong research skills through access to state-of-the-art equipment and the best scientists, including Nobel laureates at international conferences. They also learned new approaches and techniques in various research areas by being exposed to a multidisciplinary research environment, as the Prion Institute-funded researchers (i.e., principal investigators) working on many different topics related to prion and prion-like diseases.

Interviewees noted that HQP retention remains a challenge due to several contextual factors outside of the Institute’s control. As in many research fields, students are encouraged to complete their postdoctoral research elsewhere to gain experiences from different research labs. Once they leave Alberta, however, it
is unknown if they will return, and this would likely depend on many variables including their research focus, career path and the availability of opportunities in Alberta. Additionally, there is a general lack of funding for research across Canada, which can translate into low salary levels for young researchers at the postdoctoral level in particular. Salary levels are set by recommendations from national funding agencies and/or post-secondary institutions. Stiff competition for research funding means some researchers might be forced to pursue research in fields where there are more funding opportunities, which may not necessarily be in prion and protein folding research. Lastly, there are currently very few academic positions available for young researchers in Canada. This could potentially drive HQP out of research altogether, or certainly limit their ability to remain in Alberta.

The Prion Institute has capitalized on existing professional development opportunities (e.g., participation in Mitacs’ activities and events) and developed its own Expanding Horizons Program to maximize students’ chances to pursue prion research studies and find a relevant position within or outside academia. All survey respondents agreed (29%) or strongly agreed (71%) that they were supportive of a career professional development program that provides their postdocs, graduate students and lab members with opportunities to acquire skills and knowledge related to research and potential future employment opportunities. In the same vein, interviewees stated that professional development opportunities allowed HQP to learn soft skills that will help them be more competitive when seeking a job within or outside of academia. However, interview evidence suggests that additional staff may be needed to champion the Expanding Horizons Program, as it is currently not used to its full potential.
3.2 Outcome 2: Knowledge generation in fundamental and applied areas that leads to prevention, mitigation and treatment of prion and protein misfolding diseases in animals and humans

Prion Institute-funded research has maintained, and more recently increased its citation impact despite the growth in the number of publications.

Canada, and Alberta in particular, has become more specialized in prion and protein misfolding research over time. Moreover, citation impact was maintained in the early years of the Prion Institute, and recently has shown growth in citation impact despite increases in output of publications during its time of existence. Bibliometric analyses showed some encouraging trends in the average relative impact of funded peer-review publications over the last few years, and it is expected that with the completion of new prion facilities, researchers will start publishing an increasing number of high-impact publications.

Therapeutic, industry or policy applications to prevent, mitigate and treat prion and protein misfolding diseases, stemming from Prion Institute-funded research, are somewhat low at this time. This is likely a factor of the long-term and complex nature of prion and protein misfolding research and translational research in general. Evidence also indicates that the Prion Institute’s focus on developing a strong basic knowledge base might have outweighed its support for translational research. Despite this finding, promising applications are underway, including the development of both SRM-related technologies and vaccines for CWD.

Among examples of such high-quality research, several survey respondents and interviewees reported that all of the work of David Westaway’s lab is excellent fundamental science; survey respondents highlighted work that “shed new light on the natural function of the normal prion protein in relation to copper, pain and behaviour (depression)”; a survey respondent cited an article on the potential role of soil properties in the spread of CWD as “important for understanding the spread in the wild populations” and interviewees lauded the research work aiming at converting Specified Risk Material (SRM) into...
marketable materials. Interviewees often highlighted the rigorous, unbiased and high-quality project review process of the IRAC as a key factor ensuring that funded research is of excellent quality.

In terms of citation impact, as Alberta is building capacity from the ground up, it is not expected to simultaneously generate a high citation impact, which likely explains why the Average Relative Citations (ARC) of Alberta’s publications in prion and protein misfolding research has remained steady since 2006 (Figure 6). Indeed, the citation impact of a publication portfolio is intrinsically related to the size of that portfolio. The relationship between these characteristics have been described as the ‘Matthew effect’ in science, whereby as researchers’ production increases or decreases, they will experience gains or losses in terms of citations that go beyond the mere gains or losses in output size. In other words, the more a researcher, or a group of researchers, will publish, the more their popularity and network will expand in a non-linear fashion. This will provide gains in citation impact beyond the mere increase in the size of its publication output. As the Prion Institute began supporting researchers in the field in 2005, funded researchers’ reputations and network are not yet likely sufficiently developed to achieve high impact.

Furthermore, a few key informants explained that the construction of the new prion facilities and labs greatly disrupted the research process for several years for some of the key researchers funded by the Prion Institute, which provides another possible explanation for the lag in production of high-impact publications. There is an expectation that after experiencing a high production growth and high level of specialization over the period 2005–2015, and now that the facilities are close to being completed, Alberta will start producing research with a higher scientific impact within the next five to 10 years. The bibliometric analysis suggests this may already be happening, as the ARC of Alberta’s publications has been trending upward over the past five years (Figure 7).
Figure 6  Positional analysis of top publishing countries and Canadian provinces in prion and protein misfolding research, 1996–2004 (before Prion Institute’s creation) and 2006–2014 (after Prion Institute’s creation)

Note:  The size of the bubbles is proportional to the number of publications. Colouration is based on geographical locations, with Alberta in blue, Canadian provinces in red, Canada in dark red and other countries in brown. Data are not presented for entities with less than 5 publications for the given period. In addition, because of the low number of publications for Alberta, Manitoba, British Columbia and Nova Scotia in the 1996–2004 period their ARC score is prone to fluctuations. As such, results for these provinces should be interpreted carefully as one additional publication could drastically alter their position in the figure. The same applies for Nova Scotia in the 2006–2014 figures.

Source:  Computed by Science-Metrix using the Web of Science™ (Thomson Reuters)
Given the long-term nature of prion experiments, Prion Institute-funded research has yet to lead to applications related to the prevention, mitigation and treatment of prion and protein misfolding diseases in animals and humans.

The evaluation found that relatively few applications have resulted from funded projects to date, either in terms of prevention, mitigation or treatment of prion and protein misfolding diseases in animals and humans. Much of the Prion Institute’s investment has focused on building the knowledge base in this area, and thus has been less applicable in nature. Interviewees stated that prion and protein misfolding research is highly complex and often requires long-term experimentation given the incubation time of prion diseases, thus delaying its translation into therapeutic, policy or industry applications. Interview evidence indicates this is not only true for Alberta but also for the entire prion research field and also the neurodegenerative research field. No cures have been found to date for BSE and CWD, nor for Alzheimer’s and Parkinson’s diseases, though significant advances have been made in terms of identification of critical targets for drug or antibody therapy that might slow down the progression or infectivity of the diseases. Also, interviewees noted that research translation is a long process, regardless of the research field. For instance, it can take on average more than 20 years for a drug to be introduced into the market. This includes approximately 12 years to develop the idea and test the drugs, a few more years to have patents in place, and the remaining years to create the company and perform further demonstrations and tests, hopefully leading to commercialization.

While not yet fully realized, interviewees identified several therapeutic and industrial applications supported by the Prion Institute that are underway, including the following:
The development and commercialization of technologies that would allow producers to generate benefits from the conversion of SRM into marketable plastics or other materials. The Prion Institute was only involved in the early stages of this initiative (through an IDeal project) and there is now a need for substantial funding to scale up the technologies that were developed;

The development of vaccines for CWD, notably at the University of Calgary;

The development and testing of drugs for animal and human diseases, notably at the Prion Centre in Edmonton; and

A better understanding of how BSE and CWD prions are transmitted, and in the latter case between wildlife and farmed populations, which is hoped to ultimately contribute to the identification of ways to better track, prevent and manage the spreading of the diseases.

Interviewees also highlighted the role played by the Prion Institute in informing national and international policy. For instance, in 2009–10, the Prion Institute brought together the research and management communities across Canada to discuss and agree on changes to be made to the national CWD control strategy, which was renewed in 2011. Industry stakeholders also indicated that they benefit from the high-quality science produced by Prion Institute-funded researchers, as it contributes to build trust vis-à-vis the Canadian cattle industry in the context of international trade negotiations.

Interviewees expressed mixed views regarding the balance of the Prion Institute’s support for basic and applied research in the future. In general, they understood that through a slow and unpredictable progression of knowledge basic research has the potential to lead to outstanding discoveries resulting in applications in a wide range of areas that could help prevent the transmission and spreading of the diseases. They felt there is thus a need to continue to support this type of research. A key informant stated that the key objective of the Prion Institute is to support basic research and not the full development and commercialization of therapies, as these later steps require much greater funding support than the Prion Institute can afford. As previously discussed, the availability of good fundamental prion science is also important to build trust and credibility around the Canadian cattle industry in the context of international trade policy discussions.

Alternative views to that presented above were expressed as well. For instance, there are high expectations that the Prion Institute will increase its focus on translational research in the next 5 to 10 years, either in the animal or the human health area. Given the long-term nature and high uncertainty around the outcomes of basic prion research (e.g., curability of the diseases) in animal health particularly, and taking into account that the feed bans, SRM removal and surveillance programs have proven to be very effective tools to prevent the re-emergence of BSE, they argue that more efforts could be devoted to applied research projects—such as pre-commercialization of SRM-derived products—that can provide industry with tangible short-term benefits. Overall, since its inception in 2005, the Prion Institute has funded 115 basic research projects and 18 projects in targeted and applied areas. Key informants expressed that such efforts require strong industry engagement, while there are currently few investments from the livestock and related industry in translational research projects. It should be noted that commercialization is not part of the Prion Institute’s mandate. They are other organizations within the Alberta research system that focus on commercialization.
3.3 Outcome 3: Mobilization of knowledge generated for use by industry, government and researchers

Q7 – To what extent have the Institute’s promotion of knowledge transfer activities (including workshops and partnership facilitation) contributed to positive outcomes for the Institute and those it has funded?

Q8 – To what extent have the Institute’s communication and public awareness activities provided value to stakeholders?

The Prion Institute’s strong leadership in building partnerships, knowledge transfer and exchange activities provided significant value to researchers and policymakers. Of particular note is the organization of the international PRION 2011 (its first year in Canada), PRION 2013 (widely regarded as the best of the annual conferences), the SRM international discussion that was held in 2015, and regular discussions with provincial government representatives. Evidence shows that industry stakeholders are less engaged in Prion Institute events today than during the period shortly after the creation of the Prion Institute, in the wake of the BSE crisis.

The Prion Institute also developed key partnerships over the years, with PrioNet and later with the Alberta Livestock and Meat Agency and the Alberta Alzheimer Research Program co-funded by the Alzheimer Society of Alberta & Northwest Territories.

Stakeholders generally found the Prion Institute’s communication and public awareness activities to be of good quality and useful. Jay Ingram’s lectures were considered a powerful tool to educate rural communities about the latest advances in prion and protein misfolding research, although options could be explored to reach a wider audience. Communication products, such as the public annual report, the website and knowledge outreach related materials were all deemed well designed and informative.

The Prion Institute plays a key role in promoting knowledge transfer activities.

The evaluation found that the Prion Institute exerts strong leadership in promoting knowledge transfer and exchange activities that benefit its stakeholders. Sixty-one percent of researchers who responded to the survey indicated the Prion Institute brings them “significant value” in this knowledge brokering role (Figure 8). More specifically, interview and documentary data indicate the Prion Institute greatly facilitates knowledge exchange in the research and policy community by hosting, co-hosting and sponsoring conferences, workshops and seminars at the national and international level. It also aims to ensure research publications are widely distributed and convenes stakeholders to inform them of new research developments relevant to their interests.

The Prion Institute also has the function of working to catalyze research on neurodegenerative diseases—that is, to promote the transfer of prion research to research on protein misfolding diseases like Alzheimer’s and Parkinson’s that have a much more relevant impact on health worldwide. Interview data suggest it does so by supporting and promoting excellent research aimed at bridging the animal and human health research fields, such as the work done by Dr. Westaway to identify “common features in
the pathogenesis of prion disease and Alzheimer’s Disease.\textsuperscript{15,16} The Prion Institute also established important connections and organizes knowledge exchange activities (e.g., project-related meetings, public outreach) with other research organizations in Canada and abroad that are focused on human neurodegenerative diseases, such as the Alzheimer Society of Alberta & Northwest Territories and the German Center for Neurodegenerative Diseases (see details in the next section).

**Figure 8** What degree of value has the Prion Institute brought to you in its role as a knowledge broker?

![Bar chart showing the degree of value brought by the Prion Institute](chart)

Source: Survey of Prion Institute-funded researchers, 2015

Table 3 presents the types and cumulative number of knowledge mobilization activities undertaken by the Prion Institute since its inception.

**Table 3** Types and cumulative number of knowledge mobilization activities undertaken by the Prion Institute between 2005 and 2014

<table>
<thead>
<tr>
<th>Knowledge mobilization activities and outcomes</th>
<th>2005–2015</th>
</tr>
</thead>
<tbody>
<tr>
<td>Processes that engage stakeholders in knowledge exchange</td>
<td>50</td>
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<tr>
<td>Industry/government/academia workshops and similar meetings</td>
<td>6</td>
</tr>
<tr>
<td>Partnerships established between researchers, industry and policymakers</td>
<td>23</td>
</tr>
<tr>
<td>Processes, practices, products, patents and policies informed</td>
<td>8</td>
</tr>
<tr>
<td>Public awareness activities such as lectures and updates for media</td>
<td>9</td>
</tr>
<tr>
<td>Presentations to stakeholder groups</td>
<td>18</td>
</tr>
<tr>
<td>Print and web-based publications</td>
<td>23</td>
</tr>
</tbody>
</table>

Source: Prion Institute’s 2014–2015 Annual Report

Some of the events supported by the Prion Institute that were most frequently cited as highly beneficial included the following:\textsuperscript{17,18,19,20,21}
The international PRION conference: the Prion Institute and PrioNet were responsible for bringing this event to Montréal in 2011, the first time it had been held in North America, which allowed more research collaborations across continents;

NeuroPrion subsequently asked the Prion Institute to host PRION 2013, which is widely regarded as the best of the annual conferences;

The national PrP CANADA prion conference;

Annual scientific meetings where funded researchers from different labs present their work, share information and develop new collaborations;

The Members of the Legislative Assembly (MLA) breakfasts, which provide an opportunity for researchers to answer questions asked by policymakers;

The SRM international discussion, which involved national and international scientists, risk assessors and regulators to discuss the most recent advances in the development of technologies to dispose of SRM;

Workshops on BSE and CWD with industry stakeholders and researchers; and

Workshops co-hosted with international organizations from Brazil (Prion Institute employees are working on a formal agreement with the Brazilian funding agencies).

Data are currently not collected on the efficacy of knowledge transfer activities. The Prion Institute collects some information on who is attending these events, but there is no attempt to follow up to determine whether participants have changed their level of awareness, or to gain an understanding of the likelihood of them taking some sort of action as a result of their participation (namely for industry, government and other researchers who may attend these meetings, conferences or other events). This limits the ability to assess whether these events are actually making an impact.

External interviewees could not identify any other organization that plays a similar role at the national level now that PrioNet has closed. Internationally, NeuroPrion was cited often. This is a Network of Excellence dedicated to research on prion diseases that links more than 120 research teams from 52 research institutions across Europe. NeuroPrion has organized many of the international PRION conferences since its creation in 2003. However, its funding and capacity to organize events was said to have decreased over the last decade; budget information available on the NeuroPrion website indicates that the organization received €14.4 million over five years; although, it did not specify which years this covered.22

The Prion Institute also maintains connections with provincial ministries at the ministerial, ADM and operational levels to keep these stakeholders informed of the progression of research and other supported activities and influence decision-making on relevant public programs. External interviewees often noted that the strong leadership of the executive director of the Prion Institute and its supporting staff was a key success factor for the establishment and nurturing of these relationships. These connections were said to have largely contributed to the Prion Institute’s success in renewing its government funding.

Engagement with industry has proven to be more of a challenge, according to interview data. Despite efforts in networking and knowledge transfer activities—such as the recent international SRM discussion, meetings between the Institute’s executive director and industry leaders and officials, and MLA workshops21—industry is less engaged today than 10 years ago. According to key informants in this area,
the principal explanation for this is that BSE is currently not the cattle industry’s top priority. Generally, industry stakeholders also do not yet see direct benefits from SRM research, and the elk and deer industry are awaiting more tangible results from CWD research, such as vaccines or therapies. In this context, interviewees felt that further efforts could be made to reach out to the industry and bring them science with commercial potential, from which they may be more likely to directly benefit. Examples included research on topics such as early live detection and SRM.

It is important to note that the livestock industries, including the beef industry, remain supportive of the Prion Institute, as evidenced by written endorsements made of the Prion Institute during its recent request to the Government of Alberta for a continuation of funding for a third cycle of activity.

It is worthwhile noting that prion diseases and prion science happen over very long time frames, and this further complicates the timing of discovery and application in the field.

Key informants discussed the approach used by Livestock Gentec, an Alberta Innovates Bio Solutions (AI Bio) centre created in 2010 to support “research and bring the commercial benefits of genomics to the Canadian livestock industry.” While acknowledging that Livestock Gentec was created with a different set of goals, interviewees felt that it had been more successful than the Prion Institute in keeping the livestock community involved and interested in new science developments and in investing in the commercialization of genomics technologies. To quote a key informant, they were able to “put a team together, which the Prion Institute can’t, that talks the same language as producers and across generations, and they were credible.” While the Prion Institute is not expected to become a knowledge transfer driven organization, it might take this different approach into consideration as part of efforts to increase linkages with industry.

Partnerships are an important element of knowledge mobilization.

The Prion Institute actively and continuously engages and seeks partnerships with other national and international organizations, according to interviewees and documentary evidence. Research produced in the context of these collaborations, which in some cases were initiated at Prion Institute events, complements the Prion Institute’s research work and contributes to the global prion and protein misfolding research community. Key examples of such collaborations included

- a comprehensive partnership with PrioNet, a former member of the Network of Centres of Excellence;
- co-funding of several BSE, SRM and CWD projects and knowledge transfer events with the Alberta Livestock and Meat Agency;
- management of the Alberta Alzheimer Research Program co-funded by the Alzheimer Society of Alberta & Northwest Territories; and
- two ongoing joint research projects with the German Center for Neurodegenerative Diseases (with funding from the Helmholtz Association) funded under the Research Team program.

The Prion Institute and ALMA have been co-funding events and livestock industry driven projects for several years. Most recently, they did so in the context of their IDeal partnership that supports research and development projects undertaken by Alberta-based private sector organizations or public sector researchers and their private sector partners. According to a key informant, this partnership allows
ALMA to fund prion-related livestock research projects without having to run its own prion-specific competitions. From the Prion Institute’s perspective, ALMA’s funding allows them to keep supporting industry-driven research and helps them secure more support from the industry, which has traditionally been working more closely with ALMA than the Institute.

The Alberta Alzheimer Research Program is co-funded by the Alzheimer Society of Alberta & Northwest Territories, and the Prion Institute is responsible for project selection and day-to-day program management in addition to providing half of the research funding. This program provides grants and training awards to Alberta-based researchers to study the prion-like mechanism of Alzheimer’s disease and potential methods to improve the quality of life for those affected by the disease. According to a key informant, the partnership has been very effective so far, and the Prion Institute in particular has done a very good job at selecting high-quality research projects. The Institute was the major organizer of Jay Ingram’s public lectures on Alzheimer’s throughout Alberta. These lectures were well received, although the two organizations continue to work together to improve upon them.

The German Center for Neurodegenerative Diseases and the Prion Institute started collaborating on infectious diseases and on neurodegenerative diseases in 2012. Interview evidence suggests that there was a mutual interest in working together, and a decision was made to focus on prion-related research given the strengths of the two organizations in this area. Two joint research projects were developed with the funding support of the Prion Institute and a large grant from the Helmholtz Association of German Research Centres, Germany’s largest scientific organization. Principal investigators have met twice since the beginning of the projects, and a final symposium will be held at the end of the two-year projects to present joint research findings. Interview data indicate that such a cross-continental partnership is very important, as there is a global consensus among neurogenetic researchers that organizations must coordinate and distribute efforts worldwide to avoid repetition and to facilitate and accelerate the translation of research into therapeutic applications. For instance, if some research findings come to be applied in a clinical setting, several patient cohorts would be necessary to test drug interactions, which would require several research organizations to be involved in the research process.

Internal documentary evidence indicates that through its partnerships with the Alberta Livestock and Meat Agency, the Alzheimer Society of Alberta & Northwest Territories and the German Center for Neurodegenerative Diseases (Helmholtz Association), the Prion Institute leveraged an amount in the order of magnitude of $4.0 million for its research programs between 2005 and 2014. Total co-funding cash and in-kind contributions from federal and provincial organizations, academic institutions, industry and others totalled $116,403,480 for this period. Interviewees noted that ongoing efforts made by the Prion Institute to secure additional funding through the establishment of new partnerships have at least partially offset the financial impact of the closing of PrioNet, which was a key funding partner from 2006 to 2013.

The Prion Institute delivers high-quality public awareness activities and communication products.

Stakeholders generally found the Prion Institute’s communication and public awareness activities to be of good quality and useful. External interviewees deemed public outreach events highly valuable in order for the Institute to remain accountable to Alberta taxpayers and maintain public interest in supporting
prion research. Interviewees, unprompted, highlighted Jay Ingram’s lectures (e.g., Prion Diaries, Alzheimer’s Mystery) given to various Albertan rural and urban communities affected by prion diseases as a very effective and popular tool to communicate prion research progress to the general public. These lectures provide a unique opportunity for the public to interact with and ask questions of Ingram and the two experts in prion and prion-like diseases who accompany him on his tours. They also contribute to correcting misconceptions and misperceptions about prions and prion diseases that are often conveyed by the media.

A few interviewees noted that attendance at the lectures was limited, however, and suggested that other communication mechanisms be used to reach a wider audience. Options to increase attendance and accessibility are constantly being explored by the Prion Institute and Jay Ingram. Innovations such as the production of video capsules of the lectures were deemed to be potentially resource-consuming and less effective than in-person lectures. Interviewees also suggested the idea of giving more presentations to elementary school students to ensure that the next generations of citizens and producers are informed of the research advances related to prion and prion-like diseases, thus maximizing the impact of the lectures in the longer term.

Survey respondents and external interviewees were generally satisfied with the Prion Institute’s communications activities and products, such as the public annual reports, website and other promotional materials. For instance, 87% of survey respondents “agreed” (68%) or “strongly agreed” (19%) that the written communications they receive from the Prion Institute were useful to them. Interviewees found the public annual reports were well written, well designed and communicated the adequate level of information about the state of the research funded by the Prion Institute. They appreciated that the information was provided in plain language and was easy to absorb so that it is accessible to a lay audience while still useful for scientists and trainees. Interviewees also found that the Prion Institute provided them with useful communication products around knowledge transfer and exchange events, including promotional materials and meeting report summaries. The website was deemed to be user friendly and to provide useful information on upcoming activities.

Interview and survey data also revealed a high level of satisfaction with regard to the Prion Institute’s verbal communications. Indeed, 84% of survey respondents “agreed” (52%) or “strongly agreed” (32%) that the verbal communications they receive from the Prion Institute are useful to them (Figure 9). Interviewees stated that the Prion Institute’s staff maintains a constant flow of communications with researchers and is always very responsive to their requests related to the grant process or any other matter.
3.4 Relevance and efficiency

Q9 – To what extent do external stakeholders (e.g., industry, policymakers) consider Institute programs and research to be relevant? Which types are considered to be most relevant?

Q10 – To what extent have the Institute’s key policies, programs and management practices facilitated the achievement of its objectives?

Q10a – To what extent are the policies and practices in place relevant to achieving its objectives?

Q11 – Are there alternative delivery mechanisms that could be developed to improve the efficiency and/or effectiveness of the Institute in delivering on its mandate?

The grant programs offered by the Prion Institute were deemed relevant and adequate and stakeholders did not identify any major gaps, although there is a perception that the Prion Institute is focusing less on livestock industry oriented research. It is unknown whether or not those holding this perception believe this lesser focus is deliberate.

The Prion Institute is generally effective in its program delivery and management practices. Efficiencies and improved effectiveness could be realized with the implementation of some administrative changes. The Prion Institute’s position as an institution at arm’s length from government was perceived as a key contributor to the successful delivery of its activities. Overall, internal and project-level reporting requirements are adequate, aside from timeliness issues with reporting to the government and working with some partners. At the project level, researchers lauded the recent decision to move to annual reporting. The data point to the possibility that the reporting timeliness issues as well as issues related to the capturing and monitoring of financial information might be a consequence of a lack of human resources.
Prion Institute research programs are relevant.

Overall, external interview data indicate that Prion Institute’s funding support to prion research remains relevant in a context where Alberta remains highly vulnerable to these diseases, as researchers still have a very limited understanding of the behaviour of prions and prion diseases. Moreover, external interviewees believed that the Prion Institute made the right choice in expanding its scope toward human diseases while preserving its support toward animal diseases. Indeed, funded research remains aligned with the Institute’s core mandate to identify solutions to the serious scientific and socioeconomic challenges associated with prion diseases in animals, while also acknowledging that there are possible connections that should be further explored between such diseases and neurodegenerative diseases such as Alzheimer’s, Amyotrophic Lateral Sclerosis and Parkinson’s. Internal interviewees and academic and government representatives also noted that there is generally more interest from the government and the general public in seeing positive results in the human disease research area.

In this context, external interviewees found the grant program offering of the Prion Institute relevant and adequate and did not identify any major gaps. The current suite of research programs allows researchers to undertake short-term/small-scale/high-risk research projects (1 or 2 years) and longer-term/large-scale/collaborative projects (3 to 5 years). It covers the main topics of interest in both the animal and human sides of prion-related diseases, such as BSE, CWD and SRM on the one hand and Alzheimer’s disease and Parkinson’s disease on the other. The Prion Institute also funds both exploratory (Explorations) and more industry-oriented research projects (IDeal). An illustration of the wide range of topics covered by funding is shown in Figure 10, which indicates the number of awards each year since 2006, by research program.
Figure 10  Number of Prion Institute awards by program and year between 2006 and 2014

An area of concern for several interviewees, including some partners in government and industry, was that there may have been too much of a change in focus away from animal health research recently and industry-driven research in particular. A key informant suggested that the Prion Institute consider dedicating more funding toward applied/translational research programs that tend to generate more concrete and immediate benefits for the livestock industry (e.g., through the IDeal program), such as work on SRM, animal traceability and rapid testing. In particular, there is a funding gap at the pre-commercialization stage for some of the applied initiatives on SRM. As noted earlier, the Prion Institute has in fact funded a much larger number of basic research projects than applied research projects and
that commercialization is not part of the Institute’s mandate. Presently, this approach does appear to align with the Prion Institute’s more immediate outcomes, but might not adequately link to its intermediate-term outcome of usage by industry, government and researchers (i.e., Outcome 3).

Prion Institute’s key policies, programs and management practices are effective, although issues were raised with respect to the adjudication process and the timeliness of reporting.

The Prion Institute’s arm’s-length relationship with the Government of Alberta is highly effective.

Internal interviewees as well as government and academia representatives found the position of the Prion Institute (as part of AI Bio) as an institution at arm’s length from the Government of Alberta was a key contributor to the successful delivery of its activities. This allows the Institute to be more nimble and responsive to its research and industry stakeholders in that it is dedicated to one specific area of research and is not subject to all the internal administrative rules (“bureaucracies”) that a government department must follow. For example, the Prion Institute can develop partnerships and leverage funding more easily. There are fewer levels of approval than in most ministries, which provides more flexibility to support more innovative and higher-risk research projects that are not subject to political pressure or influence. The Prion Institute can carry over funding from year to year but is still subject to government accountability and budgetary rules. Interviewees stated that the Prion Institute also benefits from a relative independence from its mother organization, AI Bio, which mainly provides some administrative support related to personnel, accounting and IT matters and leaves the day-to-day running of the Institute to its staff.

Internal interviewees as well as academia and government representatives noted that while the Prion Institute operates at arms’ length from the government, efforts are made to maintain very close working relationships with the relevant ministries of innovation, agriculture and health. The Prion Institute was said to have built up a very good reputation due to the excellence of its work; this has facilitated open and ongoing discussions, and ultimately the signing of the funding renewal agreement and a satisfactory funding level.

The adjudication process allows for the selection of high-quality research projects, although some concerns were raised with respect to the composition of the International Review Advisory Council.

Interviewees and survey respondents praised the adjudication process, although some interviewees had some concerns that the composition of the International Review Advisory Council (IRAC) may lack the expertise needed in applied research and the Alberta context. The results show that nearly all survey respondents “agreed” or “strongly agreed” that the adjudication process was clear (90%) and fair (87%). Interviewed researchers, students and partners further stated that the IRAC was made up of an excellent group of reviewers and that the peer-review process was of high quality, not subject to political pressure, open to debate and discussions with staff and researchers, and flexible (i.e., allowed for slight changes in research directions when needed). Moreover, the procedures were perceived to be much more transparent in recent years, in terms of how the projects are selected and reviewed and how the funds are appropriated.
There were some concerns expressed by a few interviewees that the composition of the IRAC may be limiting the selection of some projects geared to benefit the Alberta livestock industry. Key informants felt that livestock research proposals were often not rated very highly by the IRAC, and that this was due to a lack of familiarity with the Alberta context on the part of members. In some cases these projects were able to secure funding from other partners, but to a limited extent. Alternative views suggest that this may have more to do with a lack of understanding about the intent of some of the grant programs on the part of a few applicants. Based on the data available it is not clear which is the case, but this may be an area for further investigation.

**The AI Bio grant application system is not perfectly adapted to researchers’ needs but cannot be further modified by the Prion Institute.**

Interviewees expressed mixed views regarding the AI Bio online grant application system. Evidence indicates that the AI Bio software is outdated, not user-friendly, contained inadequate financial spreadsheets and had many formatting issues and redundancies, which prevented researchers from producing a clean and professional application file. On the other hand, evidence was also found of researchers who did not face any major issues with the grant application system. In any case, interview data suggest that as the grant application system and forms are generic AI Bio tools, the Prion Institute does not have much control over them and has already made all possible adjustments. Interviewees agreed that whenever they faced difficulties, they could contact the Institute’s staff and would always receive timely and effective assistance. Almost all survey respondents (97%) “agreed” or “strongly agreed” that the Prion Institute’s contacts had been responsive to their questions and concerns (Figure 11).

![Figure 11](image)

**Figure 11**  
Level of satisfaction of survey respondents with the adjudication and funding award processes

Source: Alberta Prion Research Institute. Survey of Prion Institute-funded researchers, 2015

**Internal and project-level reporting requirements and practices are adequate, although there have been delays in the Prion Institute’s reporting to the government.**

Generally, interviewees found that internal and project-level reporting requirements were adequate, although issues were raised around the timeliness of the Prion Institute’s accountabilities toward the Government of Alberta and partners. The Prion Institute has to provide the Government of Alberta with a stand-alone annual report and a summary of highlights of its activities as part of the AI Bio annual
Staff, academia and government interviewees stated that the Prion Institute’s staff interact frequently with representatives of the Government of Alberta, which ensures a smooth reporting process at the organizational level, notwithstanding some delays in annual reporting to the Ministry of Innovation and Advanced Education. The reported content is generally output-oriented with an eventual intended move toward outcomes reporting.

There is anecdotal evidence of challenges with the timeliness of the reporting and also the coordination of calls for applications with at least one of the Prion Institute’s partners. Multiple sources, including external partners, cited possible staffing level challenges within the Prion Institute, which may explain delays in fulfilling reporting commitments vis-à-vis the Government of Alberta and partners. Interview data also suggest that the Prion Institute may benefit from additional internal administrative support to ensure that financial records are adequately tracked and documented and to accelerate the implementation of other initiatives.

At the researchers’ level, the recent decision to move to an annual reporting requirement instead of more frequent reporting was lauded by interviewees and survey respondents, particularly given the nature of many of the funded research projects. They felt that this better reflected the progression of research and allowed researchers to report substantial and meaningful achievements. Stakeholders had somewhat mixed views on the level of reporting required. A small majority of survey respondents (55%) “agreed” or “strongly agreed” that the amount of reporting required of them was adequate, which was largely corroborated by interviewees. However, more than a third of survey respondents (35%) found that the amount of reporting was inadequate (Figure 12). Interview data further suggest that compared to the Prion Institute some other funding agencies in the US and Europe require much less reporting on scientific progress (e.g., the NIH only requires a two-page report) with less strict milestones, and focus primarily on tracking financial expenditures.

Figure 12  Level of satisfaction of survey respondents with the reporting process

The Prion Institute's personnel expenses are relatively low compared to what is normally expected of a non-governmental organization.

An analysis of financial data (Table 4) shows the average proportion of personnel expenditure to total expenditures for operations and program funding is low (9.5%) for the years from 2010/11 to 2014/15. This was particularly low from 2010/11 to 2012/13 (ranging from 5.8% to 9.1%). Based on previous Science-Metrix' experiences and evaluations of other organizations, this proportion should range between 10% and 15% for non-governmental organizations. Clarification on the reason behind the increase in 2013/14 was provided by representatives of the Prion Institute; this is largely due to the Communications Manager moving to a full-time position from a contract position combined with a decrease in grant funding for that year.

Table 4  Prion Institute’s expenditures and percentages of personnel to total expenditures between 2010/11 and 2014/15

<table>
<thead>
<tr>
<th>Fiscal year</th>
<th>Personnel</th>
<th>Other operating expenses</th>
<th>Grants</th>
<th>% Personnel/Total expenditures</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010/11</td>
<td>$400,694.21</td>
<td>$428,287.64</td>
<td>$6,124,797.10</td>
<td>5.76%</td>
</tr>
<tr>
<td>2011/12</td>
<td>$425,774.84</td>
<td>$565,142.02</td>
<td>$4,663,128.47</td>
<td>7.53%</td>
</tr>
<tr>
<td>2012/13</td>
<td>$484,526.55</td>
<td>$668,176.18</td>
<td>$4,147,785.60</td>
<td>9.14%</td>
</tr>
<tr>
<td>2013/14</td>
<td>$551,663.32</td>
<td>$529,919.14</td>
<td>$2,781,310.68</td>
<td>14.28%</td>
</tr>
<tr>
<td>2014/15</td>
<td>$607,452.33</td>
<td>$372,090.85</td>
<td>$4,704,837.40</td>
<td>10.69%</td>
</tr>
<tr>
<td>Total</td>
<td>$2,470,111.25</td>
<td>$2,563,615.83</td>
<td>$22,421,859.25</td>
<td><strong>Average/year = 9.48%</strong></td>
</tr>
</tbody>
</table>

Source:  Prion Institute’s financial database

Existing alternative delivery mechanisms were not found to be more effective or efficient than the Prion Institute.

Despite identifying and examining the delivery mechanisms of other similar organizations (based on publicly available information), which included PrioNet Canada, NeuroPrion, NIH, CIHR, Genome Canada and NSERC, there were no definitive alternative mechanisms for improving efficiency and effectiveness identified through the data collected in support of the evaluation.

The only interesting discovery coming out of this review process stemmed from Genome Canada in relation to its use of research oversight committees. Genome Canada projects must now have a research oversight committee, completely independent from the project research team with no real or perceived conflicts of interest. These committees are tasked with reporting to Genome Canada on progress being made by the project. They will also make recommendations regarding continued funding and will provide advice and guidance to the research team to help ensure the projects achieve their milestones within the framework in which they were approved.30
This approach was adopted in response to an independence issue with Genome Canada’s Scientific Advisory Boards, according to information provided by a representative of Genome Canada as part of data collection outside the scope of this evaluation. This approach added a level of independence between the researchers, the reviewers and the funding organization.

This is not specifically an issue of concern for the Prion Institute at this time in the context of the IRAC; however, should issues of this nature arise in the future, as more Prion Institute-funded researchers collaborate more frequently internationally, this is a potential avenue to explore.

Aside from this discovery, only administrative adjustments to the current delivery mechanisms are needed, as described in the previous section.
4 Considerations for future operations

The findings presented in this report are demonstrative of the generally positive effect the Prion Institute has had in Alberta and on the world of prion and protein misfolding research to date. The considerations that follow are proposed with the intent of providing possible avenues for enhancing overall relevance and performance of the Prion Institute. These considerations are interrelated and their parallel implementation may be beneficial.

Consideration 1: The Prion Institute, in light of real or perceived industry disengagement, should review its mandate with an eye toward the nature of the research it will continue to fund, and whether this aligns with the overarching objectives of the organization.

There is an appetite for more translational research in the coming years within the stakeholder community. The achievement of the Prion Institute’s third outcome, “Mobilization of knowledge generated for use by industry, government and researchers” may depend on the nature of the research being undertaken. In fact, basic research provides the building blocks for applied research, but may be more limiting in the extent to which the research results can be used by industry and government stakeholders in particular. This brings into question whether the activities and outcomes of the Prion Institute are strongly aligned. Revisiting these linkages is appropriate to ensure the stakeholder community is able to more widely benefit from the research funded by the Prion Institute.

The decision on the positioning of the Prion Institute within the provincial research funding system should be an objective of consultations with the stakeholder community and subsequent strategic planning.

Consideration 2: The Prion Institute should clarify messaging in two areas: (1) the nature of the research projects that are eligible for funding under the different grant offerings made available to researchers; and (2) the potential value the stakeholder community can expect from the funded research.

The description of the grant offerings at any point in time should clearly indicate the type of research that is eligible for funding. This should include language around the extent to which the Prion Institute is seeking to fund translational research under a given grant. It also might include examples of previous projects funded under a former iteration of the grant, if applicable. This approach will assist in tempering the expectations of some researchers who may feel a particular grant provides a good opportunity to have their research funded, when in actuality the grant is not the best means for them.

Similarly, the benefits or value that industry stakeholders might derive from some of the Prion Institute-funded research should be better communicated and articulated to ensure industry does not set unrealistic expectations. This has a significant amount of relevance to Recommendation 2. It is recommended that upon implementation of Recommendation 2, the communication with industry be reviewed and adjusted to bring the stakeholder community in line with the goals of the Prion Institute.

Consideration 3: The Prion Institute should regularly undertake a workload assessment process to ensure staffing levels are adequate to meet demands more efficiently.
Regular workload assessment will provide some foresight into potential staffing challenges and solutions required for fulfilling activities, which not only include the delivery of grant programs, knowledge mobilization activities and conference organization, but also internal processes such as extrapolating data from researchers’ progress reports, ensuring strong financial management and preparing and delivering annual reports on a timely basis. Staffing levels should be adjusted up or down based on the volume of work necessary over the given period of time.

Consideration 4: Additional efforts should be made by the Prion Institute to collect impact data at, or following, knowledge transfer and community outreach activities.

The Prion Institute has made strides in collecting basic information from knowledge transfer events, but a lack of impact data makes it difficult to truly understand whether these activities are having the intended effect on industry, government and researchers. The data should be collected on a systematic basis to the extent possible, either through on-site observation, questionnaires or through post-activity follow-up surveys. The information that should be collected, at a minimum, is shown in Table 5 along with its key purpose.

Table 5  Impact data on knowledge transfer events that are to be collected by the Prion Institute

<table>
<thead>
<tr>
<th>Data / Information to be collected</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>The nature of questions being posed by the audience, as well as which stakeholders are posing the questions.</td>
<td>Provides an idea of where the interests of the stakeholder community lie, which can partially inform future grant offerings and ensure the Prion Institute remains relevant.</td>
</tr>
<tr>
<td>A self-assessment of changes in awareness about the subject matter as a result of participation in the activity.</td>
<td>Provides an indication of whether those participating have received value in terms of knowledge acquisition over and above their baseline on a particular topic, which is an important assessment of immediate impact.</td>
</tr>
<tr>
<td>A self-assessment of intent to act as a result of knowledge acquired through participation in the activity.</td>
<td>Provides an indication, as a proxy, of whether those participating will choose a certain action based on their knowledge—the action may be widely variable from one participant to the next, and may relate to other collaborative research pursuits or policy/practice decisions, depending on the composition of the audience. This begins to focus on assessing the intermediate impact.</td>
</tr>
<tr>
<td>An assessment of whether participants have actually taken action as a result of their participation in an activity.</td>
<td>This post-assessment will provide more robust evidence about whether actions within the stakeholder community are attributable to the Prion Institute’s knowledge transfer activities.</td>
</tr>
</tbody>
</table>
Appendix A – Alberta Prion Research Institute Evaluation Framework
<table>
<thead>
<tr>
<th>#</th>
<th>Evaluation questions</th>
<th>Evaluation indicators</th>
<th>Data sources</th>
<th>Methodologies</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td><strong>Outcome 1: Strong Alberta capacity for prion and protein misfolding science</strong></td>
<td>a. # of researchers funded through the Institute</td>
<td>Annual reports</td>
<td>Document review</td>
</tr>
<tr>
<td></td>
<td></td>
<td>b. Types of research funded through the Institute</td>
<td>Program files</td>
<td>Document review</td>
</tr>
<tr>
<td></td>
<td></td>
<td>c. # papers, ARC, ARIF, top 5% of Prion Institute papers related to Alberta scores</td>
<td>Bibliometric data</td>
<td>Bibliometric analysis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>d. Trends in # papers: Prion Institute &amp; Alberta; before/after creation of Prion Institute</td>
<td>Bibliometric data</td>
<td>Bibliometric analysis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>e. Comparison of Alberta with other provinces, Canada, other countries and selected comparable entities using various bibliometric indicators and trends over time</td>
<td>Bibliometric data</td>
<td>Bibliometric analysis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>f. Views on the Prion Institute and faculty at other Alberta institutions as a draw to research in Alberta</td>
<td>Researchers</td>
<td>E-survey / Interviews</td>
</tr>
<tr>
<td></td>
<td></td>
<td>g. # students/fellows participating(ed) in career enrichment opportunities through the Institute or its partners</td>
<td>Program files</td>
<td>Document review</td>
</tr>
<tr>
<td>2</td>
<td>To what extent has the Institute had an effect on the development and support of core research infrastructure in Alberta?</td>
<td>a. # of infrastructure projects funded</td>
<td>Program files</td>
<td>Document review</td>
</tr>
<tr>
<td></td>
<td></td>
<td>b. Types of infrastructure projects funded</td>
<td>Program files</td>
<td>Document review</td>
</tr>
<tr>
<td></td>
<td></td>
<td>c. Nature of use of funded facilities/equipment</td>
<td>Program files</td>
<td>Document review</td>
</tr>
<tr>
<td></td>
<td></td>
<td>d. Views on utility/importance of funded facilities/equipment</td>
<td>Researchers</td>
<td>E-survey</td>
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<td></td>
<td></td>
<td>acity</td>
<td>Faculty</td>
<td>Interviews</td>
</tr>
<tr>
<td>3</td>
<td></td>
<td>a. # papers, ARC, ARIF, top 5% of Prion Institute researchers</td>
<td>Bibliometric data</td>
<td>Bibliometric analysis</td>
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<tr>
<td>#</td>
<td>Evaluation questions</td>
<td>Evaluation indicators</td>
<td>Data sources</td>
<td>Methodologies</td>
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<td>To what extent, and by what means, has the Institute contributed to the development of highly qualified personnel?</td>
<td>b. Views on the quality of the Institute’s researchers and their respective publications</td>
<td>Academia Industry Government International partners</td>
<td>Interviews Case studies</td>
</tr>
<tr>
<td>4</td>
<td>To what extent has the Institute been able to influence the recruitment of new faculty members to Alberta institutions?</td>
<td>Albertan network of researchers, with links to the Institute</td>
<td>Bibliometric data</td>
<td>Bibliometric analysis</td>
</tr>
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<td></td>
<td></td>
<td>Views on the Institute as a draw to Alberta institutions</td>
<td>Researchers Faculty</td>
<td>E-survey Interviews</td>
</tr>
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<td></td>
<td></td>
<td>Amount of funding leveraged through partners (cash and in-kind)</td>
<td>Annual reports</td>
<td>Document review</td>
</tr>
<tr>
<td></td>
<td><strong>Outcome 2: Knowledge generation in fundamental and applied areas that leads to prevention, mitigation and treatment of prion and protein misfolding diseases in animals and humans</strong></td>
<td>a. Cases of prevention, mitigation and treatment of prion and protein misfolding diseases originating from Prion Institute-funded research</td>
<td>Academia Industry Government International partners Researchers/Students</td>
<td>Interviews Case studies</td>
</tr>
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<td></td>
<td></td>
<td>b. Views on the importance of the Prion Institute in promoting excellent research</td>
<td>Academia Industry Government International partners Researchers/Students</td>
<td>Interviews</td>
</tr>
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<td></td>
<td></td>
<td>c. # promotion activities</td>
<td>Program files</td>
<td>Document review</td>
</tr>
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<td></td>
<td></td>
<td>d. Types of promotion activities</td>
<td>Program files</td>
<td>Document review</td>
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<tr>
<td>#</td>
<td>Evaluation questions</td>
<td>Evaluation indicators</td>
<td>Data sources</td>
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<td>6.</td>
<td>What is the general regard in which the Institute, its researchers, and the quality of the research it promotes in the relevant national and international scientific community is held?</td>
<td>a. Views on the quality of the Institute's researchers and their respective publications</td>
<td>Academia Industry Government International partners</td>
<td>Interviews Case studies</td>
</tr>
<tr>
<td></td>
<td></td>
<td>b. Scientific specialization and impact of Alberta’s publications (compared to Canadian and world levels, SI, ARC, Radar with Alberta, Canada, Canadian provinces and top leading countries top provide and benchmark for the performance of Alberta)</td>
<td>Bibliometric data</td>
<td>Bibliometric analysis</td>
</tr>
<tr>
<td>7.</td>
<td>To what extent have the Institute’s promotion of knowledge transfer activities (including workshops and partnership facilitation) contributed to positive outcomes to the Institute and those it has funded?</td>
<td>a. Cases of reported positive outcomes from Prion Institute knowledge transfer activities</td>
<td>Academia Industry Government International partners Researchers</td>
<td>Interviews Case studies E-survey</td>
</tr>
<tr>
<td></td>
<td></td>
<td>b. Type of reported positive outcomes from Prion Institute knowledge transfer activities</td>
<td>Academia Industry Government International partners Researchers</td>
<td>Interviews Case studies E-survey</td>
</tr>
<tr>
<td>#</td>
<td>Evaluation questions</td>
<td>Evaluation indicators</td>
<td>Data sources</td>
<td>Methodologies</td>
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<td>8.</td>
<td>To what extent have the Institute’s communication and public awareness activities provided value to stakeholders?</td>
<td>c. Views on the importance of the Prion Institute in facilitating knowledge transfer</td>
<td>Academia Industry Government International partners Researchers Program files (survey data)</td>
<td>Interviews Case studies E-survey Document review</td>
</tr>
<tr>
<td>d.</td>
<td>Attendance of Prion Institute-sponsored/hosted knowledge transfer events</td>
<td>Program files</td>
<td>Document review</td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>To what extent do external stakeholders (e.g., industry, policymakers) consider Institute programs and research to be relevant? Which types are considered to be most relevant?</td>
<td>a. Views on relevancy of Prion Institute public awareness activities</td>
<td>Academia Industry Government International partners Researchers</td>
<td>Interviews E-survey</td>
</tr>
<tr>
<td></td>
<td></td>
<td>b. Views on the relevancy of Prion Institute programs</td>
<td>Academia Industry Government International partners Researchers</td>
<td>Interviews E-survey</td>
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<td>#</td>
<td>Evaluation questions</td>
<td>Evaluation indicators</td>
<td>Data sources</td>
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<td>10.</td>
<td>To what extent have the Institute’s key policies, programs and management practices facilitated the achievement of its objectives?</td>
<td>a. Views on adequacy of the governance structure and reporting responsibilities</td>
<td>Program management / staff</td>
<td>Interviews</td>
</tr>
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<td></td>
<td></td>
<td>b. Views on the proposal review, selection and funding awarding process</td>
<td>Researchers</td>
<td>E-survey</td>
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<td></td>
<td></td>
<td>c. Same as 1f, 1ad, 4a, 4b, 7c</td>
<td>See above</td>
<td>See above</td>
</tr>
<tr>
<td>10A.</td>
<td>To what extent are the policies and practices in place relevant to achieving its objectives?</td>
<td>a. Policy and practice decisions with documented evidentiary support (Reasons for why they are in place)</td>
<td>Administrative files, including meeting minutes</td>
<td>Document review</td>
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<td></td>
<td></td>
<td>b. Views on the effects of policies and practices of the Prion Institute</td>
<td>Program management / staff</td>
<td>Interviews</td>
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<td>Faculty</td>
<td>E-survey</td>
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<td>Researchers</td>
<td>Case studies</td>
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<td>Program files</td>
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<td>11.</td>
<td>Are there alternative delivery mechanisms that could be developed to improve the efficiency and/or effectiveness of the Institute in delivering on its mandate?</td>
<td>a. Views on alternative mechanisms</td>
<td>Program management / staff</td>
<td>Interviews</td>
</tr>
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<td></td>
<td></td>
<td>b. Mechanisms used by other research funding institutions with similar objectives</td>
<td>Faculty</td>
<td>E-survey</td>
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<td>Researchers</td>
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<td>Literature</td>
<td>Literature review</td>
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<td>Faculty</td>
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<td>International partners</td>
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Appendix B – Documents and literature reviewed

A wide range of documents and literature were examined in the context of this evaluation, including:

- Grant, funding and collaboration agreements
- Business and strategic plans
- Letters of support
- Funding guidelines and application forms
- Project applications
- Lists of funded projects
- Infrastructure funding documents
- Prion Institute’s and AI Bio’s annual reports
- Progress reports and opportunities reports
- Meetings’ terms of reference, agendas and minutes
- Media releases and announcements
- PrioNet documentation
- Congress, conference and workshop promotional materials and reports
- BSE and SRM-related external documents and articles

Appendix C – Bibliometric methodology

Creation of datasets of publications on prion and protein misfolding research

In order to prepare the bibliometric analysis supporting this evaluation, a set of publications covering the core research on prion and protein misfolding research was prepared. Using specialized keywords and a selection of journals dedicated to publishing research on this topic, relevant publications in the Web of Science database (Thomson Reuters) were retrieved, acting as the main dataset of publications for the bibliometric analysis. The selection of keywords and journals was completed with the support of the client to ensure that all relevant topics of prion and protein misfolding research were included in the analysis. Science-Metrix also used algorithms (e.g., TF-IDF) to retrieve keywords highly specific to these subjects and included these in the final query.

Assessment of the Prion Institute’s performance

For the current project, given that there was no scientific output related to prion and protein misfolding research in Alberta prior to the inception of the Prion Institute, bibliometric indicators for the whole province were used as a proxy for assessing the impact of the Institute. The selection of this approach is validated by data prepared at the level of researchers, which highlighted the fact that a large part of Alberta’s researchers active in prion and protein misfolding research were supported by the Prion Institute.

Bibliometric indicators
For this study, five indicators were prepared to assess the performance of entities, including Prion Institute-funded researchers, Canada, Canadian organizations, Canadian researchers and top publishing countries. The following are brief descriptions of each of these indicators.

**Number of papers:** This is an analysis of the number of peer-reviewed scientific papers produced by an entity (e.g., university, researcher, country) for a given time using a full-counting method. Each different entity listed in the address field on a paper receives a count of 1 for the involvement in the publication. For example, if a paper is co-authored by two researchers from Alberta, one from the United States and one from the France, the paper will be counted once for Alberta, once for the United States and once for France.

**Average of relative citations:** This is an indicator of the scientific impact of papers produced by a given entity (e.g., the world, a country, an institution) relative to the world average (i.e., the expected number of citations). The number of citations received by each publication is counted for the year in which it was published and for all subsequent years. For papers published in 2002, for example, citations received in the 2002–2014 period are counted. To account for different citation patterns across fields and subfields of science (e.g., there are more citations in biomedical research than in mathematics) and for differences in the age of publications (e.g., older papers have accumulated citations over a longer period), each publication’s citation count is divided by the average citation count of all publications that were published the same year in the same subfield, to obtain a Relative Citation count (RC). Since Science-Metrix does not compute RCs for papers with less than a two-year citation window (publication year plus two subsequent years), the ARC is not computed after 2012.

The ARC of a given entity is the average of the RCs (i.e., if an institution has 40 publications, the ARC is the average of 40 RCs, one per publication). An ARC value above 1 means that a given entity is cited more frequently than the world average, while a value below 1 means the opposite. Note that Science-Metrix does not compute the ARC for entities with fewer than 30 publications with an RC score. In some cases where numbers of publications are low, ARC scores might be presented for entities with less than 30 papers having an RC, in which case it will be displayed using a light grey font.

**Average of relative impact factors:** The ARIF is a measure of the expected scientific impact of publications produced by a given entity (e.g., the world, a country), based on the impact factors (IF) of the journals in which they were published. The IF of publications is calculated by attributing to them the IF of the journal in which they are published, for the year in which they are published. Subsequently, to account for different publication patterns across fields and subfields of science (e.g., medicine journals usually have a higher IF than mathematics journals). Each publication’s IF is divided by the average IF of all papers of the corresponding document type (i.e., a review would be compared to other reviews, whereas an article would be compared to other articles) that were published in the same year in the same subfield to obtain a Relative Impact Factor (RIF). The IF of a journal is computed over five years. For example, in 2007, the IF of a journal would be equal to the number of citations of articles published in 2006 (8), 2005 (15), 2004 (9), 2003 (5) and 2002 (13) divided by the number of articles published in 2006 (15), 2005 (23), 2004 (12), 2003 (10) and 2002 (16) (i.e., IF = numerator [50] / denominator [76] = 0.658). This indicator can be computed up to the last year available in the database (i.e., 2014).
The ARIF of a given entity is the average of its RIFs (i.e., if an institution has 40 publications, the ARIF is the average of 40 RIFs, one per publication). When the ARIF is above 1, it means that an entity scores better than the world average; when it is below 1, it means that on average, an entity publishes in journals that are not cited as often as the world average. Note that Science-Metrix does not compute the ARIF for entities with less than 30 publications with a RIF score. In some cases where numbers of publications are low, ARIF scores might be presented for entities with less than 30 papers having a relative score, in which case it will be displayed using a light grey font.

**Highly Cited Publications (HCPs):** The number and percentage of publications by an entity (e.g., the world, a country, an applicant) in the 10% most cited publications in the database is determined using the relative citation (RC) scores of publications based on all-citations, but for a minimum 3-year citation window (see above description of the ARC for the computation of RC scores). This indicator is computed only up to year 2012 since the citation window is incomplete in more recent years. Because some publications are tied based on their RC score, including all publications in the database that have a RC score equal to or greater than the 10% threshold often leads to the inclusion of slightly more than 10% of the database. To ensure that the proportion of publications in the 10% most cited publications in the database is exactly equal to 10% of the database, publications tied at the threshold RC score are each given a fraction of the number of remaining places within the top 10%. For example, if a database contains 100 publications (i.e., the top 10% should contain 10 publications). Ranked in descending order of their RC score, if the 9th, 10th, 11th and 12th publications all have the same score, they are each given a quarter of the remaining two places in the top 10% (0.5 publications of the top 10% each). In addition, in some cases, the number of places in the 10% most cited publications is not an integer (e.g., if there is 11 publications in the database, there should be 1.1 publications in the top 10%). In this case, there is a dual fractionation in case of ties at the threshold. In the above example, the paper with the highest score is given a count of 1 and the second paper is given a count of 0.1 if there are no ties in the RC score of papers at the threshold. If three papers are tied in second place behind the first paper, they are each given a weight of 0.03 (i.e., 0.1*1/3). If the top 2 papers are tied, they are each given a count of 0.55 (i.e., 1.1/2) and so on. Both full and fractional (here there can be fractions of fractions if, for example, the publication in 9th place in the top 10% has been co-authored) counting of publications are used. In the end, the number of highly cited publications is divided by the number of publications with a RC score (and not the total number of publications because some publications with no RC score are not included in this analysis—e.g., publications published after 2011), resulting in the percentage of highly cited publications. This percentage is then normalized according to the world level so that the world level is now equal to 1.00, similarly to the ARC and ARIF indicators.

**Specialization index:** The SI is an indicator of research intensity in a given entity (e.g., Alberta) for a given research area (e.g., prion and protein misfolding research), relative to the intensity in a reference entity (e.g., the world, or the entire output as measured by the database) for the same research area. The SI is the ratio of the proportion of research in a given area (relative to all research) to the proportion of research of the world in the same area. In other words, when a country is specialized in a field, it places more emphasis on that field at the expense of other research areas. Specialization is therefore said to be a zero sum game: the more one specializes somewhere, the less one does elsewhere. The SI is formulated as follows:
Where:

XS = Publications from entity X in a given research area (e.g., papers by Alberta in prion and protein misfolding research);

XT = Publications from entity X in a reference set of papers (e.g., total papers by Alberta);

NS = Publications from reference entity N in a given research area (e.g., world papers in prion and protein misfolding research);

NT = Publications from reference entity N in a reference set of papers (e.g., total world papers).

An index value above 1 means that a given entity is specialized relative to the reference entity (i.e., the world in this study), whereas an index value below 1 means the opposite.

Positional analysis: To visualize the composite performance of universities, positional analysis graphs were produced and are presented in this report. To interpret the strengths and weaknesses of a given country or province through the use of several separate indicators, Science-Metrix uses a graphical representation called positional analysis. This graphical representation logically combines three of the previously detailed indicators (number of papers, SI and ARC).

The horizontal axis of this positional graph corresponds to the SI, and the vertical axis corresponds to the ARC. These data are transformed to obtain a symmetrical distribution of possible values between -100 and +100, with zero representing the world level. The size of the bubbles is proportional to the number of papers produced by the entity.

The position of an entity in one of four quadrants can therefore be interpreted as follows:

- **Quadrant 1**: Located at the top right of the graph, this quadrant is synonymous with excellence. Entities in this quadrant specialize in the given field or domain and their activities have a high impact, meaning that their papers are more frequently cited than the world average in this domain.

- **Quadrant 2**: Located at the top left of the graph, this quadrant is synonymous with high-impact scientific production, but the entities are not specialized in the domain.

- **Quadrant 3**: Located at the bottom right of the graph, this quadrant signals specialization in the domain, whereas output impact is below the world average.

- **Quadrant 4**: Located at the bottom left of the graph, this quadrant represents the worst-case scenario, as both the intensity of activity and its impact are below the world average in the domain.
Collaboration networks: For the preparation of collaboration networks of researchers, a square matrix was built from the number of papers co-authored by all pairs of researchers. Gephi, a network graphing software, was used to process data and produce a representation of the strength of the relationships between these organizations. A “spring-embedding” algorithm was used to establish the relative locations of the institutions in the graphic representation. Each node consists of an institution represented by a circle with a size proportional to its total scientific production. Links between nodes represent collaborations between institutions. The width of the links is proportional to the number of collaborations between two institutions. Some minor modifications were made to the final network to increase readability (filtering).

Colouring of indicators: Unless otherwise specified, a gradient colouring ranging from dark green (i.e., greatly above the world level) to dark red (i.e., greatly below the world level), with white acting as the neutral state (i.e., on par with the world level), is applied to impact scores as well as the specialization indexes for ease of use in the report.

Moving averages: Because of the low number of publication in prion and protein misfolding research, it was difficult to track yearly patterns for impact indicators as low numbers of publications often result in noisy trend lines. To allow for the identification of patterns year over year, moving averages were prepared for Alberta and Canada. These moving averages use a 5-year window that is shifted by one year for each data point (e.g., 2000–2004, 2001–2005). This allows for the inclusion of larger numbers of publications per groups of years, which smooths out trend lines of impact indicators. This method enables the observation of decreases and increases in scientific impact for Alberta and Canada.
Appendix D – Master interview guide

Summative Evaluation of the Alberta Prion Research Institute

Background

1. Please briefly describe your interaction(s) with the Prion Institute, including the length of time you have interacted or been affiliated with it.

Capacity for prion and protein misfolding science

2. What were the key factors that led you to pursue prion and protein misfolding disease research in Alberta?
3. Can you comment on the level of influence of the Prion Institute in strengthening capacity for prion and protein misfolding disease research in Alberta?
4. Do you use lab facilities or equipment funded by the Prion Institute? If so, in what ways do you use this equipment? How would you be able to undertake these activities in the absence of this equipment?
5. In comparison to other prion and protein misfolding disease research funding agencies around the world, is the quality of the research and researchers funded by the Prion Institute sub-par, par, or among the best? Please explain the extent to which you find the Prion Institute-funded research to be relevant to you?

Knowledge generation

6. Are there any specific examples of cases where prevention, mitigation or treatment of prion and protein misfolding diseases was implemented as a result of research funded by the Prion Institute? If no, can you identify any research that is nearing this potential? How far off is that realization?
7. Can you comment on the importance of the Prion Institute in promoting excellent research? If the Prion Institute was not doing this, what other mechanisms are in place to promote excellent research?

Knowledge mobilization for uptake

8. Have you formed any partnerships, or undertaken any collaborative research as a result of participation in a meeting, conference, workshop or other event hosted or co-hosted by the Prion Institute? If so, please provide details of the relationship and any outcomes to date.
9. Can you comment on the importance of the Prion Institute in its role as a facilitator of knowledge exchange or knowledge transfer? Are there specific events organized or sponsored by the Prion Institute that you found particularly beneficial? In the absence of the Prion Institute as an event sponsor or host, are there other organizations in Alberta or internationally that could fill this role?
10. To what extent are the Prion Institute’s communications products useful to you? Please explain.

Relevance, efficiency and governance

11. To what extent do the Prion Institute’s public awareness activities provide information relevant to your interests?
12. Of the Prion Institute’s programs/grant offerings, which do you find to be most relevant to you? If you are a researcher, which grants have you applied for? Which grants were you successful in obtaining?

13. Do you feel that the arm’s-length relationship between the Prion Institute and the Government of Alberta has had an impact on the Institute’s success in delivering its mandate?

14. Are accountabilities and reporting requirements well understood by those affiliated with the Prion Institute? Please explain.

15. Are the policies and practices of the Prion Institute clear and understandable? Are they achieving what they are intended to achieve? Please explain.

16. Do you have any comments on ways to improve program delivery through the Prion Institute, either from past experiences, or through familiarity with other similar research agencies?
Appendix E – E-survey questionnaire

Alberta Prion Research Institute Survey of Researchers

Introduction

The Alberta Prion Research Institute has contracted Science-Metrix to conduct a summative evaluation of the Institute’s first 10 years of operation. As part of this evaluation we are surveying funded researchers. This evaluation is an important external assessment of how effective and efficient the Prion Institute has been in achieving its desired outcomes. The final report will be provided to the Ministry of Innovation and Advanced Education to showcase the impact of the Alberta Prion Research Institute, the importance of building scientific capacity in our province and the need to continue to fund excellent prion research. The survey takes approximately 10 minutes to complete. If you are unable to complete the questionnaire on your first visit, you can save and leave the survey and return to the point at which you left by simply clicking on the link in your email invitation. Each link is uniquely coded, so please do not share your link with others. The survey will be available for a limited time. Your responses will remain anonymous, used only for the purpose of this evaluation. For any technical problems or to discuss the use of this e-survey for the evaluation, please contact Jason Russo at 1-800-994-4761 ext. 303; email: jason.russo@science-metrix.com. Please use the buttons in the survey to navigate (“Next”, “Clear”, “Save” and “Back”), rather than the buttons of your web browser.

Background

1. In which year did you first receive funding through the Prion Institute?

- 2005
- 2006
- 2007
- 2008
- 2009
- 2010
- 2011
- 2012
- 2013
- 2014
- 2015
- Not sure

2. How many grants have you received from the Prion Institute, in total?
3. In which year did you receive your most recent funding grant?

- 2005
- 2006
- 2007
- 2008
- 2009
- 2010
- 2011
- 2012
- 2013
- 2014
- 2015
- Not sure

4. Were you attracted from outside Alberta to conduct prion and/or protein misfolding research at an Alberta institution?

- Yes
- No

Influence of the Prion Institute

5. Please rank the following factors in terms of their level of influence on your decision to conduct prion and/or protein misfolding research at an Alberta institution (1=Greatest influence and 7=Least influence).

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<thead>
<tr>
<th>Rank</th>
<th>Most influential</th>
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<tbody>
<tr>
<td>1</td>
<td>2</td>
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<td>3</td>
<td>4</td>
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<tr>
<td>5</td>
<td>6</td>
</tr>
<tr>
<td>7</td>
<td>Least influential</td>
</tr>
</tbody>
</table>
Access to industry
Faculty reputation
Geographic location
Lab facilities available
Prion Institute funding for prion research
Reputations of other researchers at Alberta institutions
University reputation

6. What other key factors, if any, influenced your decision to conduct prion and/or protein misfolding research in Alberta?

7. In the absence of the Prion Institute's research funding, would you still have chosen to conduct prion and/or protein misfolding research at an Alberta institution?

- Yes
- No
- Not sure

Adjudication, Funding and Reporting

8a. To what extent do you agree or disagree with the following statements about the adjudication, funding and reporting processes?

- The Prion Institute's adjudication process is clear.
- The Prion Institute's adjudication process is fair.
Funding is awarded in a timely manner (actual funds, not award letters).

Reporting requirements attached to funding agreements have/had adequate timelines.

The amount of reporting required of me is/was adequate.

I am/was asked to provide complete information on the status of my research as part of reporting requirements.

The Prion Institute contacts with whom I have engaged are responsive to my questions or concerns.

I am supportive of a career professional development program that provides my postdocs, graduate students and lab members with opportunities to acquire skills/knowledge related to research and potential future employment opportunities.

8b. Please suggest improvements for the Prion Institute's adjudication, funding award and reporting processes?

Knowledge Transfer and Exchange

9. The Prion Institute plays a knowledge broker role in that it hosts or sponsors events to bring together researchers, government representatives and industry representatives to share information. What degree of value has the Prion Institute brought to you in its role as a knowledge broker?

○ Significant value

○ Some value
10a. To what extent do you agree or disagree with the following statements related to knowledge transfer and exchange, for example via workshops, conferences and public lectures?

The written communications I receive from the Prion Institute are useful to me.

The verbal communications I receive from the Prion Institute are useful to me.

The Prion Institute's public awareness activities are relevant to me.

The Prion Institute undertakes knowledge transfer and exchange activities that are suitable for my specific area of research.

10b. Please suggest improvements for the Prion Institute's knowledge transfer and exchange activities.

Relevance and Utility

11. How do the lab facilities available to you for your Prion Institute-funded research compare with the lab facilities you are familiar with at institutions outside of Alberta? They are:

- Significantly better
- Better
12. How would you compare the quality of prion-related research conducted by researchers within Alberta to that of researchers at institutions outside the Province? They are:

- Significantly better
- Better
- About the same
- Worse
- Significantly worse
- Don't know
- Not applicable

Relevance and Utility

12b. Please cite any particularly notable publications from Alberta-based prion and/or protein misfolding researchers other than you.


12c. What is it about the publication(s) you cited that makes it(them) particularly notable?


12d. Has this research you cited above been translated into action by industry, government or other stakeholders?

- Yes
13. Please provide any other comments that may assist in assessing the efficiency, effectiveness or relevance of the Prion Institute.

End of the survey

Thank you for your time. To submit your responses please click on the “Submit” button. Please note, as soon as you submit the survey, you will no longer be able to change your answers.
Appendix F – Case studies

Innovation case study – Value-added products from Specified Risk Material

Case characteristics

Thematic area: Innovation
Funding program: IDeal Program
Outcome(s) covered: Outcome 2: Knowledge generation in fundamental and applied areas that leads to prevention, mitigation and treatment of prion and protein misfolding diseases in animals and humans
Amount of funding: $660,000 from the Prion Institute for two projects
Date of initiation: 2009
Date of closure: 2012

Background/history

The Prion Institute has been directing part of its funding support toward research projects focused on Specified Risk Material (SRM), as part of its mandate to address the economic and social consequences of prion diseases. SRM are the tissues of ruminant animals in which BSE prions concentrate and that can no longer be passed for human food (e.g., brains, eyes, spinal cord). The cattle industry can no longer generate revenues from SRM and slaughterhouses and rendering plants must pay to dispose of considerable amounts of them.31 Researchers, including Prion Institute-funded scientist Dr. David Bressler, are working on identifying ways to convert these tissues to materials that can be sold for a profit.

There are several methods for disposing of SRM, including incineration, land-filling, composting, thermal hydrolysis and caustic hydrolysis.32 Interview data indicated incineration of SRM generates high levels of sulphur, while land filled with SRM can no longer be used for agricultural purposes; in both cases, the way the SRM are disposed of does not generate any form of revenue for the cattle and rendering industry. However, according to summaries of the 2015 International Discussion on Specified Risk Material,33 given existing technologies, incineration and land-filling remain the cheapest acceptable methods of disposal available at present. Caustic or thermal hydrolysis yielding only waste or fertilizer were not deemed cost-effective on a large scale; however, these methods have great potential if higher value applications can be developed to utilize the protein hydrolysates produced. Composting methods and other methods of anaerobic digestion appear to show great potential for reducing prion infectivity.

At the International Discussion on Specified Risk Material, particular attention was paid to two approaches: (1) the use of SRM as feedstock for fungi that would break down the proteins in such a way that they would no longer be infectious, and (2) acid or base hydrolysis and thermal hydrolysis whereby prions are converted through chemical processes into “building blocks” for new polymers such as plastics.34 The latter methods have been the main focus of Dr. Bressler’s studies that were carried out initially with the support of the Prion Institute.

Outputs/outcomes
Documentary and interview evidence indicate that Dr. Bressler carried out two SRM-related projects with the support of the Prion Institute.

The first project (Development of Value-Added Applications Derived from Rendering By-product Streams, including Specified Risk) was conducted in partnership with Sanimax, a leading company in rendering—that is, the conversion of waste animal tissue into value-added materials. The main direct outcome of this project was the transformation of prion-infected SRM into safe and potentially marketable materials. Both the thermal and caustic hydrolysis methods were used to hydrolyze prion proteins of SRM. The proteinaceous material, then no longer infectious, was then recovered and cross-linked into high-performance polymers or plastics.

Dr. Bressler collaborated with the Woodbridge Group, the Alberta Biomaterials Development Centre and the Tessenderlo Group, a multi-billion dollar chemical company based out of Belgium. Their aim was to commercialize the products resulting from the project, possibly for car casing or federal postal packaging purposes.

Indirect benefits also resulted from this project in the form of professional development and training for a research associate, a postdoctoral fellow, two PhD students, and two summer students in the areas of protein chemistry, advanced agrichemical analysis and biorefining conversions. Interview data indicate a large proportion of the Prion Institute funding contribution was used to cover the costs associated with these HQP.

The total funding for the project was $2,275,000, of which $204,000 came from the Alberta Prion Research Institute, and the remainder from the SRM-CAP, PrioNet Canada (academic researcher support), the Sanimax Corporation and the University of Alberta (Table 6).

Table 6  Funding allocated to the Development of Value-Added Applications Derived from Rendering By-product Streams, including Specified Risk project

<table>
<thead>
<tr>
<th>Funding source</th>
<th>Funding amount</th>
</tr>
</thead>
<tbody>
<tr>
<td>Prion Institute’s contribution</td>
<td>$510,000</td>
</tr>
<tr>
<td>University of Alberta</td>
<td>$1,125,000 (in-kind)</td>
</tr>
<tr>
<td>Sanimax</td>
<td>$340,000 (half of which is in-kind)</td>
</tr>
<tr>
<td>PrioNet</td>
<td>$300,000</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>$2,275,000</strong></td>
</tr>
</tbody>
</table>

Source: 2012 Progress Report

The second project (Development of natural fibre composites using rendered animal co-products derived from specified risk materials) followed up on the first and was conducted in partnership with the Biorefining Conversions and Fermentation Laboratory at the University of Alberta Centre for Prions and Protein Folding Diseases and the Alberta Biomaterials Development Centre. The Prion Institute and ALMA each provided $150,000 for this project.
The main objective of the project was to “determine how SRM rendered products subjected to both alkaline and thermal hydrolysis and set with various crosslinkers (…) could serve as a natural matrix for natural fibre residues from Alberta’s thriving agricultural industry.” The project resulted in a renewable biocomposite material platform. The project also looked at confirming the safety of the products resulting from the hydrolysis methods, which is an important concern for the industry. In collaboration with the Wood Pellet Association of Canada, and with financial support from ALMA, Dr. Bressler also explored the use of hydrolyzed SRM proteins as feedstock to produce industrial adhesives.

These two Prion Institute-funded projects led to several patent applications and scientific publications. However, at this point, the technologies are still at the lab scale/patenting stage and have not been scaled up to the industry level. Interview evidence suggests that substantial additional funding is needed to bring these technologies to market. Note that Dr. Bressler has not applied for Prion Institute funding since the second project ended in 2013, as none of the grant programs were relevant to his commercialization needs.

Interview evidence indicates that there were several challenges associated with the two SRM projects. First, due to a disagreement around reporting requirements and major internal organizational issues within Sanimax, Sanimax ended its partnership during the first project, which considerably reduced the level of industry support to Dr. Bressler’s SRM work at the time.

Secondly, there is a current lack of funding support for testing at the industrial level and commercializing the developed products. These late stages of the R&D process typically require substantial amounts of funding that most agencies are unable or unwilling to commit to. A key informant felt that public funding programs tend to provide commercialization funding to companies and not individual researchers. Interview data indicate material scientists and industry stakeholders are also hesitant to invest in these types of technologies that are based on SRM source materials (i.e., initially unsafe materials).

Lessons learned

Interviewees believe that the two Prion Institute-funded projects generated potentially marketable products. Unfortunately, the absence of large-scale funding to move the projects down the commercialization path in all likelihood means the potential impact to industry and society will not be realized in the near term. It is not clear whether the Prion Institute can have a role in further moving this research along due to the fact that commercialization is not part of its mandate.

List of documents reviewed


**List of interviews conducted**

The responses of six interviewees were used in the context of this case study, including:

- Four government representatives
- One researcher
- One staff member
Case study on Partnerships – PrioNet

Case characteristics

Thematic area: Partnerships

Funding program: N/A

Outcome(s) covered: Outcome 1: Strong Alberta capacity for prion and protein misfolding science

Amount of funding: N/A

Date of initiation: 2005

Date of closure: 2013 (funding ceased in 2012, but the organization did not close until 2013)

Background/history

In its 2004 budget speech, the Government of Canada made a commitment to help address the economic impacts of the BSE crisis. A Network of Centres of Excellence dedicated to research on BSE and other prion diseases was established, and came to be known as PrioNet Canada. The Government of Alberta, whose provincial economy was particularly affected by the BSE crisis, followed suit and committed to investments in this research field as well. This ultimately led to the creation of the Alberta Prion Research Institute (Prion Institute).

Created as a reaction to the same crisis, these two organizations operated in close partnership from their time of initiation until PrioNet ceased to exist in 2013. The partnership was renewed in 2009 with the joint signing of a Memorandum of Agreement (MoA) for three years from 31 March 2009 to 31 March 2012. According to the MoA, the objective of this partnership was for PrioNet and the Prion Institute to “work collaboratively to further the common objective of advancing prion research in light of the socio-economic impact of TSEs and related diseases.” More specifically, the partnership aimed to “(a) [...] better understand the pathobiology, (b) the development of ante-mortem diagnostic technologies, and (c) the effective preventative and therapeutic modalities and the socio-economic impact of TSEs and related diseases.”

Activities/outputs

The main activities undertaken under the PrioNet-Prion Institute partnership included the following:

- The coordination of project selection processes:
  - While each organization administered separate funding calls consistent with their research programs, they made efforts to coordinate the application process and timing of the calls.
- The co-funding of research projects:
  - PrioNet and the Prion Institute could decide to fund projects independently or to co-fund projects selected under their respective research programs and
  - PrioNet would typically fund the top researchers in their competition, which could include a few from Alberta.
The Prion Institute would provide up to 25% of funding for PrioNet competitions for successful Alberta-based researchers.

The coordination of support to large-scale project research infrastructure:

- Interview evidence suggests PrioNet did not have the capacity to meet all infrastructure needs and was more focused on direct research costs, while the Prion Institute could make important capital investments specific to Alberta to facilitate prion research;

The coordination of training activities for highly qualified personnel (HQP);

Shared resources for the recruitment of prion researchers to Alberta;

Regular coordination/co-hosting of respective annual scientific and knowledge exchange meetings, e.g. annual scientific meetings, workshops, focus groups and public lectures;

Co-hosting PRION 2011 and Baden to Banff;

The co-sponsoring of knowledge outreach and public awareness events in the order of a 50/50 magnitude;

The coordination of communications during events and in the media through mutually inter-dependent communication protocols, press releases and educational materials; and

The development of collaborations with stakeholders in the prion research field, including with academia, industry and international prion research organizations.

In addition, the boards of directors for the two organizations were integrated, as there were several members who sat on both. Occasional joint annual board meetings were held to facilitate communication and coordination on matters related to governance, research or researcher recruitment.

Numerous outputs in the form of workshops, conferences and others resulted from the Prion Institute-PrioNet partnership. The Prion Institute’s annual and progress reports spanning 2007 to 2015 identified many jointly undertaken activities and corresponding outputs, as summarized in the table below.
Table 7  Main outputs resulting from the PrioNet-Prion Institute partnership
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<tbody>
<tr>
<td>Co-hosting/co-sponsoring of events</td>
<td>With CIHR, the Prion Institute and PrioNet co-sponsored and co-held the annual national prion conference, PrP CANADA 2012, in Toronto, which was attended by 173 researchers and trainees from across the country</td>
<td>In 2011, co-hosted the world’s largest international prion research conference, which was held for the first time in Canada in Montreal. The conference was attended by over 500 researchers and prion stakeholders from around the world</td>
<td>Co-hosted an exhibit booth at the international prion conference in Salzburg in 2010</td>
<td>Co-hosted an exhibit booth at the international prion conference in Salzburg in 2010</td>
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<td></td>
<td>Co-funded workshops related to chronic wasting disease (CWD) in Saskatoon in 2011, exploring CWD management issues and risks in Canada to inform an update of the National Chronic Wasting Disease Control Strategy</td>
<td>Co-hosted the 13th Baden-to-Banff meeting in 2009 with NeuroPrion (3rd meeting held in Canada), an international prion meeting, which was attended by 80 invited researchers and students</td>
<td>Co-presented at the prion conference in Madrid in 2008</td>
<td>Co-presented at the prion conference in Madrid in 2008</td>
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<td></td>
<td>Co-hosted BSE-related meeting in Banff in 2012 to discuss the status of the Canadian cattle and beef industries in 20 years</td>
<td>Co-hosted the annual PrP CANADA conference in Toronto in 2008 and in Edmonton in 2009</td>
<td>Co-presented at the prion conference in Edinburgh in 2007</td>
<td>Co-presented at the prion conference in Edinburgh in 2007</td>
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<td></td>
<td>Co-conducted a breakfast information session for MPs and senators</td>
<td>Co-sponsored a workshop in Calgary on Specialized Risk Materials in 2008, which was attended by 65 prion researchers, producer groups, industry, and government regulators</td>
<td>Co-sponsored the Student and Young Professional Association (SYPA) meeting, which allows students and young professionals to network with each other</td>
<td>Co-sponsored the Student and Young Professional Association (SYPA) meeting, which allows students and young professionals to network with each other</td>
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<td></td>
<td>Co-sponsored Jay Ingram's public lectures in 2007 in Alberta and across Canada</td>
<td></td>
<td>Co-sponsored Jay Ingram's public lectures in 2007 in Alberta and across Canada</td>
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<tr>
<td>Held joint internal meetings</td>
<td>Co-hosted the annual scientific meeting at which researchers currently funded by the two organizations presented their work</td>
<td></td>
<td>Co-hosted the annual scientific meeting in 2010 for researchers currently funded by the two organizations to facilitate collaborations between researchers and students. Held a joint science and policy meeting between the two boards to discuss prion research strategies.</td>
<td></td>
</tr>
<tr>
<td>Project co-funding/joint selection</td>
<td>PrioNet funded 3 Alberta projects under its Open Call II and IV</td>
<td>In 2011, co-funded over 10 projects selected under APRI’s research programs with investigators from Edmonton and Calgary</td>
<td>The Prion Institute was responsible for the review of co-funded proposals for PrioNet Canada’s Open Calls. Established a joint review expert panel and co-funded projects under PrioNet Bootstrap/the Prion Institute’s IDeal. PrioNet Bootstrap/the Prion Institute’s IDeal programs collaboration to foster collaborative projects between academia and industry. The Prion Institute reviewed researchers’ proposals made under PrioNet Canada’s Open Competition.</td>
<td></td>
</tr>
<tr>
<td>Award co-funding</td>
<td>Co-funded the $20k Dr. Don Rix Memorial Prion Mentorship Award provided to an outstanding prion researcher to mentor a graduate student, postdoctoral fellow or young professional in prion research</td>
<td></td>
<td>Created joint review panels to assess jointly funded special awards and prizes such as the Dr. Don Rix Mentorship Award.</td>
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<tr>
<td>Infrastructure</td>
<td></td>
<td></td>
<td>Co-funded rodent testing suite at UBC available for use by Prion Institute investigators.</td>
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<tr>
<td>Other Joint activity</td>
<td></td>
<td></td>
<td></td>
<td>Co-sponsored an evaluation of the costs and benefits of ante mortem BSE testing</td>
</tr>
</tbody>
</table>

Source: Prion Institute’s Annual, Progress and Transitional Reports\(^38,39,40\)
Outcomes/impact

Interview evidence suggests that over the seven years the partnership was active, the two organizations worked synergistically toward the achievement of common objectives through shared governance and joint initiatives and strategic leveraging of provincial and federal funding. Interviewees stated that there was little overlap between the two organizations because both organizations had been working closely together since the beginning. The co-funding model, according to interview data, enabled Canada to stand on the world stage as one of the most outstanding countries in prion research.

Interviewees highlighted the following outstanding examples of positive outcomes that resulted from the collaboration between the Prion Institute and PrioNet:

- Joint recruitment efforts, mainly through researchers’ grants from PrioNet and major infrastructure investments from the Prion Institute, attracted some of the very best prion and protein misfolding researchers to Canada and Alberta.
- Prion Institute-PrioNet co-funding of projects allowed Alberta-based researchers to develop fruitful collaborations with prion and protein folding researchers from other provinces, such as Saskatchewan.
- PrioNet and the Prion Institute were the catalysts for the broadening of PRION, the international prion conference, to non-European countries when they brought it to North America for the first time in 2011; this conference contributed to increased cross-continent collaborations.
- Trainees gained more skills and support than they would have without the two organizations working together, mainly because of the additional funding available to support these activities.

Challenges/solutions

The most significant challenge associated with the partnership occurred with the dissolution of PrioNet in 2013. While not all interviewees observed changes following the closing of PrioNet, others identified repercussions, in particular on the level of support provided to researchers. Now that the Institute is the “only player in town” and PrioNet is no longer available to co-fund some of the research programs, the Prion Institute is not able to fund as many researchers over as long a time as it once could. Also, collaborations with researchers outside of Alberta are not as active as during the time period in which PrioNet was providing support.

While the Prion Institute has remained actively engaged in sponsoring and hosting national and international events, senior management must now make difficult choices about whether to create new grants or ensure the participation of researchers in international events in a given year. In this context, it has become more challenging for the Prion Institute to maintain the right balance between these two forms of support to achieve optimal positioning for Alberta-based prion research and researchers.

Despite the challenges, interview data indicate that the Prion Institute has maintained delivery of its core research programs and outreach activities without PrioNet’s support, notably through the establishment of new partnerships with the Alberta Livestock and Meat Agency (ALMA) and the Alzheimer Society of Alberta and Northwest Territories. In addition, interviewees felt that the Prion Institute has gained visibility at the national and international level now that it is the only major player in prion research funding in Canada.
Lessons learned

Overall, the partnership between PrioNet and the Prion Institute was a positive experience that provided researchers with access to more project funding and knowledge exchange/networking opportunities. The Prion Institute appears to have made wise use of its resources to maintain its core activities and support after PrioNet was dissolved; however, the one area worth exploration by the Prion Institute is the level of collaboration occurring between Alberta-based researchers and researchers outside of the province. These collaborations are more limited than during the time in which a national funding source was available for support.

List of documents reviewed


List of interviews conducted

The responses of 14 interviewees were used in the context of this case study, including:

- Five researchers
- Three government representatives
- Three staff members
- Two academia representatives
- One partner
Outreach case study – Jay Ingram’s public lectures

Case characteristics

Thematic area: Knowledge outreach

Funding program: N/A

Outcome(s) covered: Outcome 3: Mobilization of knowledge generated for use by industry, government and researchers

Amount of funding: N/A

Date of initiation: 2007

Date of closure: Ongoing

Background/history

According to his biography, Jay Ingram is a science broadcaster and writer, and was co-host of the Discovery Channel’s science show Daily Planet for 16 years. Earlier in his career, Ingram hosted CBC Radio’s Quirks and Quarks and earned two ACTRA Awards, one for Best Host. For 10 years, he wrote articles for popular children’s publication Owl Magazine. He wrote a weekly science column for the Toronto Star for 12 years, and is currently a columnist for Canadian Wildlife magazine. He has won awards for his efforts to popularize science, and is particularly skilled in making complex scientific issues interesting, relevant and accessible to many different audiences.

Jay Ingram has been collaborating closely with the Prion Institute to deliver public lectures on prions, prion diseases and prion-like protein diseases since 2007. Kevin Keough, Executive Director of the Prion Institute, first approached Ingram while they were both members of the PrioNet’s board of directors, knowing that he was an effective and popular science communicator.

They both recognized that there was a need to provide communities across Alberta with a better understanding of prions, how they work and what prion diseases might be present in their area. The intent of the lectures was to ensure that people in these communities, including local decision-makers and industry stakeholders, were aware of the state of prion science in Alberta and of the risks associated with prion and prion-like diseases. Interviewees indicated that such lectures are particularly relevant in Alberta, where all the past BSE cases were found and where CWD is currently spreading from the southern to the western and northern areas of the province. Agriculture is also the second most important economic sector of the province after the oil industry.

Activities/outputs

Jay Ingram gave several series of public lectures in different locations throughout Alberta. Among the most successful were The Prion Diaries, which discussed topics related to prions and prion diseases such as BSE and CWD, and The Alzheimer’s Mystery, discussing prion-like protein diseases. Each series of lectures held in three different locations attracted between 200 and 400 people. Ingram also made
presentations at PrP CANADA, the national prion conference, and his presentations were featured in local and national newspapers and news broadcasts.

According to interview data, Ingram’s lectures typically start by the presentation of a case or story that will “grab” people’s attention, followed by the provision of basic biological information on prions and description of prion diseases by the two Prion Institute-funded scientists who accompany him on his tours. The speakers also discuss the challenges associated with the research conducted on BSE and CWD. After approximately 40 minutes of presentations, the audience is then invited to ask questions of the scientists and Ingram.

Some of the key lectures given by Jay Ingram since 2007 are listed in Table 8.

Table 8  Examples of public lectures given by Jay Ingram between 2007 and 2015

<table>
<thead>
<tr>
<th>Year</th>
<th>Topic/Nature</th>
<th>Location</th>
<th>Attendees</th>
</tr>
</thead>
<tbody>
<tr>
<td>Various years</td>
<td>Plenary speaker PrP Canada Conference</td>
<td>Various locations</td>
<td>Variable</td>
</tr>
<tr>
<td>2007</td>
<td>Cultural and scientific mysteries associated with prion diseases</td>
<td>Calgary, Edmonton, Lethbridge</td>
<td>400+</td>
</tr>
<tr>
<td>2011</td>
<td>Prion diseases in animals and humans</td>
<td>Red Deer, Grande Prairie, Medicine Hat</td>
<td>Unknown</td>
</tr>
<tr>
<td>2012</td>
<td>Prion and prion-like protein diseases (Prion Diaries)</td>
<td>Lethbridge, Olds, Vermilion</td>
<td>600+</td>
</tr>
<tr>
<td>2013</td>
<td>Prion and prion-like protein diseases (Prion Diaries)</td>
<td>Fort McMurray, Edmonton, Calgary</td>
<td>300+</td>
</tr>
<tr>
<td>2014</td>
<td>Prion and prion-like protein diseases (Prion Diaries)</td>
<td>Pincher Creek, Lloydminster, Brooks</td>
<td>200</td>
</tr>
<tr>
<td>2015</td>
<td>Prion research and its relevance in the study of Alzheimer’s disease (Alzheimer’s Mystery)</td>
<td>Calgary, Edmonton, Lethbridge</td>
<td>400+</td>
</tr>
</tbody>
</table>

Source: Prion institute Annual and Progress Reports42,43,44

Outcomes/impact

Interview and documentary data suggest that the lectures had, and continue to have, a positive impact on those who attend by raising their levels of awareness and understanding of prions, and prion and protein misfolding diseases. It is important to note that neither Ingram nor the Prion Institute systematically
collect feedback from the participants to confirm changes in awareness or understanding. These changes in levels of awareness and understanding are considered short-term impacts. Interviewees believe these presentations should be repeated over time to sustain the impact.

**Challenges/solutions**

A few interviewees noted that attendance at the lectures was limited and suggested that other communication mechanisms be used to reach a wider audience. One key informant noted that the Prion Institute should put more efforts into reaching out to industry stakeholders in particular. However, a few other interviewees argued that the goal of the lectures is to reach out to rural and urban communities that are affected by prion diseases, and that in this context having 100–150 people in attendance is reasonable. The lectures in the rural communities have the potential to reach industry members. Options to increase attendance and accessibility are constantly being explored by the Prion Institute and Ingram. Innovations such as the production of video capsules of the lectures are deemed to be potentially resource-consuming and less effective than in-person lectures. Interviewees also suggested giving more presentations to elementary school students to ensure that the next generations of citizens and producers are informed of the research advances related to prion and prion-like diseases, thus maximizing the impact of the lectures in the longer term.

**Lessons learned**

Jay Ingram’s public lectures are generally well received; many interviewees across all groups spontaneously referred to these as a very effective means to educate the general public about prions and prion diseases. The Prion Institute may consider expanding the scope of the lectures by using complementary communication tools and further engaging a wider audience such as industry stakeholders.

A key best practice identified through the interview process is that more time will be allocated to the Q&A period to allow people to ask all the questions they might have on the topics covered during the initial presentations. The goal of this approach is to ensure changes in knowledge can occur, as a result of key questions being answered.

**List of documents reviewed**


**List of interviews conducted**
The responses of 19 interviewees were used to inform this case study, although many of these only provided short statements on the quality and usefulness of the lectures.

- Nine researchers
- Five government representatives
- Two academia representatives
- Two students
- One partner
Building capacity in prion science case study – Infrastructure funding at the Universities of Alberta and Calgary

Case characteristics

Thematic area: Infrastructure

Funding program: N/A

Outcome(s) covered: Outcome 1: Strong Alberta capacity for prion and protein misfolding science

Amount of funding: $2 million to the University of Alberta and $1.9 million the University of Calgary

Date of initiation: 2006 (University of Alberta) and 2009 (University of Calgary)

Date of closure: Ongoing

Background/history

Since its inception, the Prion Institute has made substantial investments toward the construction and renovation of prion research facilities and the acquisition of equipment at the University of Calgary and the University of Alberta. The main objective of these investments was to dedicate laboratory space to biosafety level 2 or level 2+ containment facilities. Such levels allow researchers to conduct lab research with infectious prion materials in a safe environment. These infrastructure investments were instrumental in attracting expert prion researchers such as Dr. David Westaway and Dr. Hermann Schätzl to Alberta’s two primary universities in 2006 and 2013 respectively.45

Activities/outputs

University of Alberta

The Centre for Prions and Protein Folding Diseases (CPPFD) was created in 2006.46 Interviewees explained that Dr. David Westaway, a key international researcher in the areas of prions and other neurological diseases, was appointed Director of the Centre in 2006 and several other key prion researchers joined the lab over the years, including Dr. Valerie Sim, Dr. Judd Aiken, Dr. Debbie McKenzie and Dr. Holger Wille.

According to internal documents, the Prion Institute awarded a total of $2 million to David Westaway at the University of Alberta to cover infrastructure costs related to the renovations of the building used to host the CPPFD. The University of Alberta allocated $820,000 for the planning, design and engineering consultancy in addition to providing a building that was renovated to house the CPPFD, now housed in the newly renamed Brain and Aging Research Building.

Interview and internal documentary data indicate that the design of the new/renovated infrastructure and the choice of equipment were based on the needs of research projects approved by the Prion Institute and the recommendations of Dr. Westaway.47 Some of the key facilities and pieces of equipment acquired with this funding include a small, enhanced level 2 lab (‘‘CL2+’’) for tissue culture of prion-infected cells, a DNA preparation room and electron microscopes.
Dr. Westaway leveraged Prion Institute funding to secure an additional $22.9 million in contributions for construction and equipment from other sources including the Canada Foundation for Innovation (CFI), the Alberta Science and Research Investments Program (ASRIP – another Government of Alberta program), the Natural Sciences and Engineering Research Council (NSERC) and the University of Alberta. Since 2008/2009, the Prion Institute has also allocated operational support for the new lab in the order of $250,000 annually under the SRM-CAP program.

The renovations occurred in two phases, according to interview data. The first small containment lab was completed in 2008/2009, the two main labs including a large-animal facility were operational in late 2010 and the last containment lab in late 2011. The electron microscope area was attached to the containment lab in 2014/15. In 2010, the CPPFD received the Canadian Food Inspection Agency’s (CFIA) and the Public Health Agency of Canada’s (PHAC) certification for a contaminant lab handling prion disease agents: the Tissues Culture Centre Suite. As of November 2015, the CPPFD is planning for a third phase involving the creation of a translational facility for drug testing that will require the conversion of office space into lab space and the use of animal lab space in an adjacent building for animal imaging and medicinal chemistry.

The 2011 and 2012 project progress reports indicate that the CPPFD supports a total of 60 researchers and technicians, including seven top prion researchers with labs in the facility. The researchers now have access to “27,000 square feet of lab and office space, on three building floors of a prion research-dedicated building, containing communal, state-of-the-art equipment and small animal facilities.” The CPPFD was said to be the largest prion specific containment lab in Canada. The CPPFD also supports other researchers within and outside of Alberta who collaborate with the core research team.

University of Calgary

Interview evidence indicates that in 2005/06 the University of Calgary’s Faculty of Veterinary Medicine started funding the construction of the Prion Research Unit: a site dedicated to prion research within the University of Calgary’s Health Research Innovation Centre. One of the main objectives of the construction of the unit was to attract senior prion researchers to Calgary to conduct research on animal prion diseases and human prion-like diseases in the wake of the BSE crisis. The document review indicates that the University of Calgary experienced difficulties in recruiting senior researchers due to the lack of infrastructure available to work with infectious prions. Internal documents indicate that in 2009, a funding request was submitted to the Prion Institute by two world-renowned prion researchers—Stefanie Czub and Markus Czub—who were working in the faculty. However, Dr. Stefanie Czub was also affiliated with the CFIA and based in Lethbridge and not fully dedicated to the University of Calgary’s research group, according to interviewees. In 2012, the University was able to attract two high-calibre researchers dedicated to the lab: Hermann Schätzl and Sabine Gilch. Other researchers have joined the lab over the years, according to interviewees. Dr. Stefanie Czub is currently still working as a Research Manager at the Canadian Food Inspection Agency in Lethbridge and is Adjunct Professor at the University of Calgary.

The Prion Institute provided funding for the acquisition of offices and equipment to be used in the shared laboratory for processing and analysis of specimens containing infectious prions. In addition, Prion
Institute funding was used to cover 50% of the costs for the construction of an animal facility. The remaining 50% was funded by a CFI grant for the development of virology research space at the University of Calgary. Some additional lab space for other recruits was also built, although without the Prion Institute’s support. In 2013/2014, the construction was completed, and the facility received Biosafety Level (BSL) 2+ containment certification from the CFIA and PHAC.

Interview evidence indicates there are currently seven prion and protein misfolding researchers using the prion research site at the University of Calgary. Key research areas of the lab include social, economic and human health impacts of TSEs, Prion Protein (PrP) function and molecular and cellular determinants of PrP conversion, pathophysiology of prion and misfolded protein diseases and TSE surveillance and control, according to internal documents.

Internal documents indicate total Prion Institute investment amounts to $1.9 million for three years, while leveraged funds from the Canada Foundation for Innovation, the Canadian Institutes of Health Research and the University of Calgary total $2.3 million (Figure 13). Since 2012, the Prion Institute has also allocated $300,000 over three years to cover operational costs.

**Figure 13** Funding requested for the construction and equipment of the University of Calgary’s Prion Research Unit

<table>
<thead>
<tr>
<th>Purpose of funding</th>
<th>Cost</th>
<th>Funding from the Prion Institute</th>
<th>Secured funding sources</th>
<th>Funding from sources other than the Prion Institute</th>
</tr>
</thead>
<tbody>
<tr>
<td>Construction of prion laboratories and associated offices, and animal facility for virus and prion infections</td>
<td>$2,964,402</td>
<td>$633,726</td>
<td>CFI, CIHR, U of C</td>
<td>$2,330,676</td>
</tr>
<tr>
<td>Equipment for shared biochemistry/cell culture labs and BSL2 animal facility</td>
<td>$1,316,100</td>
<td>$1,316,100</td>
<td>$0</td>
<td></td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>$4,280,502</strong></td>
<td><strong>$1,949,826</strong></td>
<td></td>
<td><strong>$2,330,676</strong></td>
</tr>
</tbody>
</table>

Source: Prion Institute internal documents

**Outcomes/impact**

The Prion Institute made important infrastructure investments and successfully leveraged large amounts of funding from the CFI, CIHR and the Universities of Alberta and Calgary, all of which led to the creation of state-of-the-art prion-dedicated facilities and equipment that attracted some of the best researchers in the world in prion and prion-like diseases. Documentary and interview data indicate that the dramatic growth in Alberta prion research capacity between 2005 and 2015 is largely attributable to these infrastructure investments and subsequent recruitments. Interviewees stated that the new labs allowed researchers, especially those at the CPPFD, to compete with the best prion and prion-like diseases researchers in the world; only a few other labs in the United States and the United Kingdom were said to be slightly better equipped and funded, notably because they benefit from higher levels of philanthropic and public funding support respectively.
Converse viewpoints were expressed by some key informants. For example, there was reference to delays outside of the Prion Institute’s control associated with setting up the new labs. These delays have somewhat slowed the research production and impact of key researchers, which is expected to increase within the next few years now that the construction and renovations are close to completion.

Interviewees also noted that by providing undergraduate and graduate students access to the best equipment and techniques in the field the Prion Institute contributes to building a pool of highly talented HQP, some of whom may choose to pursue prion or prion-related research in the future.

Finally, interview data suggest there was an important unintended outcome realized by the two universities. Given the biosafety levels as well as the state-of-the-art equipment available, other researchers from non-prion labs often use the research space. In some instances, it was reported that collaborations have occurred as a result of this sharing, although details on the nature of the collaborations and/or their outcomes are not clear.

**Challenges/solutions**

The renovation of the CPPFD faced several challenges as pointed out by interviewees. For instance, a key obstacle was the fact that the initial $2 million grant was deemed insufficient by a key informant to upgrade and equip the full centre; therefore, substantial additional funding from other sources had to be identified and secured. It was explained that this process considerably delayed the completion of the renovations and subsequent research production (i.e., publications).

Second, interviewees from both the CPPFD and the University of Calgary stated that key researchers have faced difficulties in securing operational funding to cover lab management and animal caretaking related costs. Interview data indicated that the CPPFD has had difficulties negotiating funding to cover the costs associated with service contracts for the maintenance of research equipment. This issue is expected to be resolved by the Prion Institute through the implementation of an operational fund that will allow the two universities to share funding annually to cover new equipment, service contracts and staffing.

**Lessons learned**

Supporting the construction of prion-dedicated facilities in collaboration with other major contributors, in particular at the University of Alberta, is a key achievement of the Prion Institute that was found to be a key driver of Alberta prion research capacity building over the past 10 years.

Operational support was said to be essential to ensure labs can operate efficiently. In a context where equipment maintenance expenses cannot be shared with other labs because they are used exclusively for prion research, attention should be paid to ensure that such operational support is made available on an ongoing basis, either through the Prion Institute or other funders’ programs.

**List of documents reviewed**


List of interviews conducted

The responses of seven interviewees were used in the context of this case study, including:

- Four researchers
- Two academia representatives
- One staff member
Highly Qualified Personnel (HQP) case study – Individuals involved in HQP recruitment/training

Case characteristics

Thematic area: Development of highly qualified personnel

Funding program: N/A

Outcome(s) covered: Outcome 1: Strong Alberta capacity for prion and protein misfolding science

Amount of funding: N/A

Date of initiation: 2005

Date of closure: Ongoing

Background/history

The Prion Institute does not provide direct salary support to young researchers; however, more than two-thirds of the grant money it provides is used to pay the salaries of graduate students, postdoctoral fellows, lab technicians and research associates. The Prion Institute has recognized the importance of training and development of students and young researchers in the field. This activity supports the Institute’s objective to contribute to the development and retention of highly qualified personnel (HQP). As such, the Prion Institute provides training opportunities and professional development support through funding programs and the provision of networking activities. According to interviewees, given the shifting landscape in academia, whereby there are fewer job opportunities available for new cohorts of researchers, these opportunities are considered highly useful.

Activities/outputs

Annual reports\(^59\) indicate that overall between 2005 and 2015

- More than 370 young research trainees and research assistants were supported and trained by the Prion Institute; and
- 177 students and fellows have taken advantage of career enrichment opportunities provided through the Prion Institute and its partners.

The Prion Institute contributes to the training of undergraduate and graduate students as well as postdoctoral fellows, mainly through the provision of funding for travel to conferences, indirect salary support for participation in ongoing research projects, and career enrichment opportunities.\(^60,61,62,63,64\)

- Additional direct funding support for travel to the national PrP\(^{\text{CANADA}}\) and international PRION conferences; for example, 13 young researchers received a total of $15,750 to attend PRION 2014 in Italy, 27 trainees received a total of $16,000 in travel support to attend PRION 2013 conference in Banff, and approximately 100 HQP went to the 2010 PrP\(^{\text{CANADA}}\) in Ottawa. The remaining costs of their travel were covered through principal investigators’ grants.
- Students and HQP also participate in and present posters of their work at annual scientific meetings where all researchers and their teams currently funded by the Prion Institute are invited.
to present and share knowledge with their peers; for example, up to $1,000 was provided to 
students to attend a scientific meeting with Brazilian researchers.

- HQP participate in funded research projects; interviewees reported that HQP from high school 
  students to research assistants were actively involved in projects and treated as peers; for example, 
designed and executed experiments, or contributed to the writing of the scientific publications.
  - The Prion Institute does not provide direct funding in the form of salary support, 
scholarships or fellowships to students and HQP. However, researchers are encouraged 
to allocate part of their grants to students and young professionals such as post- 
doctoral fellows, research associates and technical assistants involved in their research 
group (44 students and HQP were supported by the projects awarded in 2013–2014).

- The Prion Institute and PrioNet provided support to meetings organized by the Student and 
  Young Professional Association (SYPA). These meetings are aimed at providing students and 
HQP with opportunities to network with each other, learn about research conducted in Canada 
and discuss topics related to career development.

- The Expanding Horizons Program provides trainees with professional development sessions to 
broaden their hard and soft skills outside of the lab; for example, 60 trainees have participated in 
the program to gain skills related to grants crafting, careers in industry, interview skills and media 
training.
  - Students and HQP also receive support to participate in professional development 
  workshops held during the national prion conference; for example, 18 students were 
involved in communications workshops at PrP CANADA in Toronto.

- The Prion Institute dedicates funding for awards targeted at young researchers or young 
researchers’ training, such as the International Young Researcher Prize for an outstanding 
contribution by a young researcher or student, the Dr. Don Rix Award to support an outstanding 
prion researcher to mentor a graduate student, postdoctoral fellow or young professional in prion 
research.

Outcomes/impact

Interviewees’ responses showed that the Prion Institute’s supported activities have had a positive impact 
on HQP’s research production and quality, scientific collaborations, professional development and career 
advancement. Examples of benefits from participation in conferences, scientific meetings and in projects 
cited by interviewees include the following:

- acquisition of high-level research skills through access to state-of-the-art equipment and exposure 
to the best scientists, including Nobel laureates at international conferences;
- acquisition of skills and techniques from various prion sub-research fields through exposure to a 
multidisciplinary research environment because the Prion Institute recruited researchers from 
various backgrounds;
- learning of soft skills that will help HQP be more competitive when seeking a job within and 
outside of academia (e.g., lab management, communications, industry work, government policy);
- opportunity to develop side projects as a result of participation in networking events (there is 
evidence that one student-driven project was translated into a formal grant proposal); and
employment opportunities in other labs resulting from networking in scientific meetings and at conferences, especially for postdoctoral students.

Challenges/solutions

Retention of HQP remains a challenge in Alberta due to several contextual factors outside of the Prion Institute’s control. As in many research fields, students are encouraged to complete their postdoctoral research elsewhere to gain experience from different research labs. Once they are outside of Alberta, however, it is not known whether they will return; this would likely depend on many variables including their research focus, their career path and the availability of opportunities in Alberta.

Additionally, there is a general lack of funding for research, which translates into low salary levels for young researchers at the postdoctoral level in particular. Stiff competition for research funding means some researchers may be forced to pursue research in fields where there are more funding opportunities, which may not necessarily be in prion and protein folding research.

Lastly, there are currently very few academic positions available for young researchers in Canada. As with competition for funding, competition exists for faculty positions across Canada. It could potentially drive HQP out of research altogether, or certainly limit their ability to remain in Alberta.

The Prion Institute has capitalized on existing professional development opportunities (e.g., participation in Mitacs' activities and events) and developed its own Expanding Horizons Program to maximize students’ chances to stay in academia and pursue prion research studies in Alberta. However, interview evidence indicates that additional staff may be needed to champion this program, which is currently not operating to its full potential.

A noteworthy suggestion was made to provide funding to students to work in other labs so that they can experience all the facets of prion research.

Lessons learned

Overall, there was a high level of interviewee satisfaction with the Prion Institute’s HQP recruitment and training support, in particular with its focus on professional development. In this context, there is a need to ensure that the Expanding Horizons Program is delivered to its full potential. A key step would be to communicate the program including its potential benefits to HQP.

List of documents reviewed


List of interviews conducted

The responses of nine interviewees were used in the context of this case study, including:

- Four researchers
- Two academia representatives
- Two students
- One staff member
Appendix G – References

1 Frédéric Forge and Jean-Denis Fréchette, “Mad Cow Disease and Canada’s Cattle Industry” (Canada: Parliamentary Information and Research Service, July 12, 2005), http://www.parl.gc.ca/Content/LOP/researchpublications/prb0301-e.htm.
4 Denoted key informants are those with a particularly detailed and/or historical understanding of the Prion Institute, its processes, its mandate and its goals.
8 Alberta Prion Research Institute, “2011 Progress for Achieving Outcomes” (Alberta Prion Research Institute, 2011).
11 Mitacs is a national, not-for-profit organization working with universities and public and private sector organizations to support applied and industrial research in mathematical sciences and related fields. They deliver a research internship program whose main objective is to facilitate access to private sector employment opportunities to highly educated graduates. The organization also offers R&D management programs, professional skills development and international research training. Mitacs claims to have supported more than 10,000 research internships, trained more than 19,000 student and postdoc career-skills participants, and supported more than 1,300 international research collaborations since 1999.
17 Alberta Prion Research Institute, “2011 Progress for Achieving Outcomes.”
18 Alberta Prion Research Institute, “2012 Progress for Achieving Outcomes.”
25 For more details on the objectives, activities and outcomes of this partnership, see the Partnership Case Study.
27 Ibid.
28 Personnel expenditures include the salaries of full-time, part-time and temporary staff, benefits, staff travel and professional development costs.
29 Other operating expenditures such as program administrative and knowledge translation expenses.
32 Ibid.
33 Ibid.
34 Ibid.
35 Alberta Prion Research Institute, “2012 Progress for Achieving Outcomes.”
36 Ibid.
37 Alberta Prion Research Institute, “2011 Progress for Achieving Outcomes.”
38 Ibid.
42 Alberta Prion Research Institute, “2012 Progress for Achieving Outcomes.”
45 Alberta Prion Research Institute, “2012 Progress for Achieving Outcomes.”
46 Ibid.
47 Ibid.
48 Ibid.
50 Alberta Prion Research Institute, “2012 Progress for Achieving Outcomes.”
51 Ibid.
52 Alberta Prion Research Institute, “2011 Progress for Achieving Outcomes.”
53 Alberta Prion Research Institute, “2012 Progress for Achieving Outcomes.”
54 Ibid.
55 Ibid.
57 Alberta Prion Research Institute, “2012 Progress for Achieving Outcomes.”
60 Alberta Prion Research Institute, “2011 Progress for Achieving Outcomes.”
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65 Mitacs is a national, not-for-profit organization working with universities and public and private sector organizations to support applied and industrial research in mathematical sciences and related fields. They deliver a research internship program whose main objective is to facilitate access to private sector employment opportunities to highly educated graduates. The organization also offers R&D management programs, professional skills development and international research training. Mitacs claims to have supported more than 10,000 research internships, trained more than 19,000 student and postdoc career-skills participants, and supported more than 1,300 international research collaborations since 1999.