# PHSA RESEARCH METRICS REPORT

9th Annual Report

Fiscal Year 2016–17

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**PHSA Research Committee** 

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# **ACKNOWLEDGEMENT**

The following report is prepared for the Provincial Health Services Authority (PHSA) Board of Directors on an annual basis to present data related to the Framework for PHSA Research Metrics (see Appendix 2). As an academic health sciences organization, PHSA works in close partnership with the University of British Columbia and other academic partners, including Simon Fraser University, University of Victoria, and University of Northern BC.

The research activities described in this report are made possible only through the collaboration and partnership of PHSA, its agencies and research entities, and its academic partners.













# **TABLE OF CONTENTS**

| PHSA Research Metrics Fiscal Year Summary: PHSA Overall   | 6  |
|---|----|
| Executive Summary   | 8  |
| PHSA Aggregate Analysis   | 10 |
| Producing and Advancing Knowledge   | 10 |
| Figure 1. Total PHSA Research Funding by Funding Type and Sub-Type by Fiscal Year                         | 10 |
| Figure 2. Total PHSA Research Funding by Fiscal Year and Type   | 11 |
| Figure 3. Percentage of PHSA Research Funding by Funding Source Category by Fiscal Year                   | 11 |
| Figure 4. Percentage of PHSA Research Funding by RISe Sector and Fiscal Year                              | 12 |
| Figure 5. Percentage of PHSA Research Funding by RISe Sector and Agency                                   | 12 |
| Table 1. PHSA Annual Grant Application Success Rate   | 13 |
| Figure 6. Total Number of Publications by Agency and Category   | 13 |
| Building Research Capacity  | 14 |
| Figure 7. Total Number of PHSA Researchers by Category and FY   | 14 |
| Table 2. Number of Funded Studies, PI's, UBC Co-PI's and Award Amount by Agency                           | 14 |
| Figure 8. Total Number of PHSA Trainees by Fiscal Year  | 15 |
| Figure 9. Total Number of PHSA Trainees by Type by Fiscal Year  | 15 |
| Achieving Economic Benefits and Innovation  | 16 |
| Figure 10. Total # of Invention Disclosures, Provisional Patent and PCT Applications Filed by Fiscal Year | 16 |
| Figure 11. Total # of National Provisional Patent Applications Filed and Issued by Fiscal Year            | 17 |
| Figure 12. License/Assignment Agreements and Spin-Off Companies by Fiscal Year                            | 17 |
| Advancing Health and Policy Benefits  | 18 |
| Figure 13. Total # of Clinical Trials and Total Cumulative Subject Enrollment by Fiscal Year              | 18 |
| Figure 14. PHSA Percent of Clinical Trial Grant Funding Type: Active and Terminated Trials within the FY  | 18 |
| Figure 15. Classification of Benefits Summary for FY 2015–16 for All Agencies & Registries                | 19 |
| Table 3. Key Agency Achievements—Outcomes Survey  | 20 |
| BC Cancer Agency (BCCA)   | 21 |
| Producing and Advancing Knowledge   | 21 |
| Figure 16. Total BCCA Research Funding by Funding Type and Sub-type by Fiscal Year                        | 21 |
| Figure 17. Percentage of BCCA Research Funding by Funding Source Category by Fiscal Year                  | 22 |
| Figure 18. BCCA Research Funding by RISe Sector, Funding Source Category and Type by Fiscal Year          | 23 |
| Table 4. BCCA Annual Grant Application Success Rate   | 24 |
| Figure 19. Total Number of BCCA Publications by Type and Category   | 24 |
| Building Research Capacity  | 25 |
| Figure 20. Total Number of BCCA Researchers by Category and Fiscal Year                                   | 25 |
| Figure 21. Total Number of BCCA Trainees by Type and Fiscal Year  | 25 |

|    | Achieving Economic Benefits and Innovation  | 26 |
|----|---|----|
|    | Figure 22. BCCA TDO Invention Disclosures, Provisional Patent and PCT Applications by Fiscal Year               | 26 |
|    | Figure 23. BCCA TDO National Patent Activity by Fiscal Year   | 27 |
|    | Figure 24. BCCA License Agreements and Spin-Off Companies by Fiscal Year  | 27 |
|    | Table 5. TDO IP Related Revenue   | 28 |
|    | Advancing Health and Policy Benefits  | 28 |
|    | Table 6. BCCA Clinical Trials   | 28 |
|    | Figure 25. BCCA Percentage of Clinical Trial Grant Funding Type – Active and Terminated Trials within the FY    | 29 |
|    | Table 7. BCCA Outcomes Survey Responses   | 29 |
| ВС | Children's Hospital Research (BBCHR)  | 32 |
|    | Producing and Advancing Knowledge   | 32 |
|    | Figure 26. Total BCCHR Research Funding by Funding Type and Sub-type by Fiscal Year                             | 32 |
|    | Figure 27. Percentage of BCCHR Research Funding by Funding Source Category by Fiscal Year                       | 33 |
|    | Figure 28. BCCHR Research Funding by RISe Sector, Funding Source Category and Type by Fiscal Year               | 34 |
|    | Table 8. BCCHR Annual Grant Application Success Rate  | 35 |
|    | Figure 29. Total Number of BCCHR Publications by Type and Category  | 35 |
|    | Building Research Capacity  | 36 |
|    | Figure 30. Total Number of BCCHR Researchers by Category  | 36 |
|    | Figure 31. Total Number of BCCHR Trainees by Type   | 37 |
|    | Achieving Economic Benefits and Innovation  | 37 |
|    | Figure 32. BCCHR Invention Disclosures, Provisional Patent and PCT Applications Filed by Fiscal Year            | 37 |
|    | Figure 33. BCCHR National Patent Activity by Fiscal Year  | 38 |
|    | Figure 34. BCCHR License/Assignment Agreements and Spin-off Companies by Fiscal Year                            | 38 |
|    | Table 9. BCCHR IP Related Revenue   | 39 |
|    | Advancing Health and Policy Benefits  | 39 |
|    | Table 10. BCCHR Clinical Trials   | 39 |
|    | Figure 35. BCCHR's Percentage of Clinical Trial Grant Funding Type – Active and Terminated Trials within the FY | 40 |
|    | Table 11. BCCHR Outcomes Survey Responses   | 40 |
| ВС | Mental Health and Substance Use Services (BCMHSUS)  | 44 |
|    | Producing and Advancing Knowledge   | 44 |
|    | Figure 36. BCMHSUS Research Funding by Funding Type and Sub-type by Fiscal Year                                 | 44 |
|    | Figure 37. Percentage of BCMHSUS Research Funding by Funding Source Category by Fiscal Year                     | 45 |
|    | Figure 38. Total BCMHSUS Research Funding by RISe Sector, Funding Source Category and Type by Fiscal Year       | 46 |
|    | Figure 39. Total Number of BMHSUS Publications by Type and Category   | 47 |
|    | Building Research Capacity  | 47 |
|    | Figure 40. Total Number of BCMHSUS Researchers by Category  | 47 |
|    | Figure 41. Total Number of BCMHSUS Trainees by Category   | 48 |
|    | Advancing Health and Policy Benefits  | 48 |
|    | Table 12. BCMHSUS Clinical Trials   | 48 |
| ВС | Centre for Disease Control/UBC Centre for Disease Control (BCCDC/UBC CDC)                                       | 49 |
|    | Producing and Advancing Knowledge   | 49 |
|    | Figure 42. Total BCCDC/UBC CDC Research Funding by Funding Type and Sub-type by Fiscal Year                     | 49 |
|    | Figure 43. Percentage of BCCDC/UBC CDC Research Funding by Funding Source Category by Fiscal Year               | 50 |

| Figure 44. Total BCCDC/OBC CDC Research Funding by R1Se Sector, Funding Source Cate            | egory                |
|--|----------------------|
| and Type by Fiscal Year  | 5-                   |
| Figure 45. Total Number of BCCDC/UBC Publications by Type and Category                         | 52                   |
| Building Research Capacity   | 52                   |
| Figure 46. Total Number of BCCDC/UBC CDC Trainees by Type                                      | 52                   |
| Advancing Health and Policy Benefits   | 53                   |
| Table 13. BCCDC/UBC CDC Clinical Trials  | 53                   |
| Table 14. BCCDC/UBC CDC Outcomes Survey Responses  | 53                   |
| Women's Health Research Institute (WHRI)   | 57                   |
| Producing and Advancing Knowledge  | 57                   |
| Figure 47. Total WHRI Research Funding by Funding Type and Sub-type by Fiscal Year             | 57                   |
| Figure 48. Percentage of WHRI Research Funding by Funding Source Category by FY                | 58                   |
| Figure 49. Total WHRI Research Funding by RISe Sector, Funding Source Category and Type        |                      |
| Figure 50. Total Number of WHRI Publications by Type and Category                              | 60                   |
| Building Research Capacity   | 6-                   |
| Figure 51. Total Number of WHRI Trainees by Type   | 6-                   |
| Figure 52. Total WHRI Membership by Category   | 62                   |
| Advancing Health and Policy Benefits   | 62                   |
| Table 15. WHRI Clinical Trials   | 62                   |
| Figure 53. WHRI's Percentage of Clinical Trial Grant Funding Type: Active and Terminated Trial | als within the FY 63 |
| Table 16. WHRI Outcomes Survey Responses   | 63                   |
| Registries & Datasets  | 67                   |
| Advancing Health and Policy Benefits   | 67                   |
| Table 17. Research Activities Supported by Registries and Datasets                             | 69                   |
| Table 18. Provision of Data to external Data Sets by Registry                                  | 70                   |
| Figure 54. Ranking of Predominant Nature of Research Questions Using Data from the Regist      |                      |
| Figure 55. Research Access Requests and Approvals from Registry/Dataset by Fiscal Year         | 7                    |
| Figure 56. Percentage of Benefit Sub-type by Type for FY 2016–17                               | 72                   |
| Table 19. Registry/dataset Patient and System Benefits   | 73                   |
| Appendices   | 76                   |
| Appendix 1: Example Research Questions by Registry/Dataset                                     | 76                   |
| Appendix 2: Framework for PHSA Research Metrics  | 79                   |
| Appendix 3: Research Metrics Working Group Membership  | 80                   |
| Appendix 4: Glossary   | 8-                   |

# PHSA RESEARCH METRICS FISCAL YEAR SUMMARY: PHSA OVERALL

|                                 |    |  | FY 2014–15    | FY 2015–16    | FY 2016–17    |
|---------------------------------|----|--|---------------|---------------|---------------|
| Indicator                       |    | Key Measure Description  | Value         | Value         | Value         |
|                                 | 1a | Total Annual Grant Awards by Type (including Major CFI Infrastructure grants)        | \$131,838,156 | \$159,747,871 | \$131,522,583 |
|                                 |    | Salary Awards  | 12,751,039    | 13,306,431    | 14,205,812    |
|                                 |    | Infrastructure Awards  | 16,675,937    | 45,471,139    | 2,121,562     |
|                                 |    | Operating Grants   | 98,107,211    | 97,099,541    | 110,287,899   |
|                                 |    | Other  | 4,303,969     | 3,870,760     | 4,907,310     |
| /ledge                          | 1b | Total Annual Grant Awards by RISe Sector (including Major CFI infrastructure grants) |               |               |               |
| nov                             |    | Government   | 67,395,627    | 92,657,320    | 57,406,340    |
| βg                              |    | Non-Profit   | 48,906,960    | 55,124,321    | 57,394,081    |
| ncir                            |    | Industry   | 15,535,569    | 11,966,230    | 16,722,161    |
| Producing & Advancing Knowledge | 1c | CIHR Annual Grant Application Success Rate - PHSA Overall/ Nat'l *                   |               |               |               |
| ing                             |    | 2015-09 Foundation Live Pilot #2   | See footnote  | See footnote  | 11.5%/13.2%   |
| quc                             |    | 2016-10 Foundation Grant (Open)  |               |               | 15%/12.7%     |
| Pro                             |    | 2016-09 Project Grants   |               |               | 35.6%/20.7%   |
|                                 | 1d | Total # of Publications with Agency Author   |               |               |               |
|                                 |    | BCCHR  | 679           | 738           | 840           |
|                                 |    | BCCA   | 524           | 341           | 335           |
|                                 |    | WHRI   | 328           | 412           | 476           |
|                                 |    | BCCDC  | 227           | 228           | 211           |
|                                 |    | BCMHSUS  | 83            | 95            | 80            |
| r <sub>o</sub>                  | 2a | Total # of Research Trainees   | 1,232         | 1,293         | 1,687         |
| Building Research<br>Capacity   | 2c | Total # of Researchers (excluding Category 4— Affiliate Investigator Category)       | 724.5         | 769.5         | 810           |
| ing l                           |    | Category 4—Affiliate Investigator  | 40            | 41            | 10            |
| Build                           | 2e | Indirect Costs Program Grants (Tri-Council only)                                     | \$4,057,550   | \$4,010,692   | \$4,273,685   |

| Indicator   |    | K. M D   | FY 2014–15   | FY 2015–16   | FY 2016–17   |
|---|----|--|--------------|--------------|--------------|
|   |    | Key Measure Description  | Value        | Value        | Value        |
| -   | 3a | # of Invention disclosures   | 60           | 52           | 50           |
| r (Kluo   |    | # of Provisional Patent applications filed                                       | 29           | 25           | 20           |
| omic<br>atior   |    | # of PCT applications filed  | 7            | 6            | 5            |
| Economic<br>Innovation  |    | # of Patents Filed/Issued  | 41/9         | 25/28        | 16/137       |
|   | 3b | # Active License Agreements  | 159          | 163          | 167          |
| # Active License Agreem # of Spin-off Companies  # Prelated revenue—Rea |    | # of Spin-off Companies  | 9            | 10           | 12           |
| Ach<br>Ben  |    | IP related revenue—Realized Revenue  |              |              |              |
| BC  |    | BCCA   | \$174,696.69 | \$274,585.00 | \$258,712.91 |
|   |    | BCCHR  | \$28,758.00  | \$41,295.44  | \$23,665     |
| alth & fits   |    | Clinical Trials (including Non-PHSA PIs utilizing PHSA facilities and resources) |              |              |              |
| Cumulative Subject Enrollm  4b,c,d Registries as Research Reso          |    | # active trials at the end of the FY   | 551          | 519          | 541          |
|   |    | Cumulative Subject Enrollment at end of FY                                       | 63,146       | 58,450       | 92,366       |
|   |    | Registries as Research Resources   |              |              |              |
|   |    | # of Research Requests/Approvals   | 216/204      | 189/180      | 264/250      |

<sup>\*</sup>CIHR phased out the Open Operating Program beginning in Fall 2014 and replaced it with the Foundation and Project Scheme Competitions so comparisons to previous FY's are not applicable.

### **EXECUTIVE SUMMARY**

This is the ninth annual Research Metrics Report, based on the Framework for PHSA Research Metrics previously approved by the PHSA Research Committee (see Appendix 2, pg. 79). All previously reported qualitative and quantitative metrics have been updated to include data for FY 2016–17 in the Framework's four categories; **Producing & Advancing Knowledge, Building Research Capacity, Achieving Economic Benefits & Innovation**, and **Advancing Health & Policy Benefits**.

The results for each metric are provided in a one-page snapshot utilizing combined information from each participating PHSA research entity. These include BC Children's Hospital Research (BCCHR), British Columbia Cancer Agency (BCCA), Women's Health Research Institute (WHRI), PHSA Mental Health and Substance Use Research Program (BCMHSUS) and British Columbia Centre for Disease Control/UBC Centre for Disease Control (BCCDC/ UBC CDC). Also included in this report are the statistics for researchers operating at one of the PHSA agencies with no research institute affiliation. While there are a number of researchers associated with the BC Emergency Health Services (BCEHS), BC Renal Agency, Cardiac Services BC, and BC Transplant, they conduct their research under the auspices of the academic affiliation they hold. As such, research activities are not attributed directly to these PHSA agencies and they are accordingly not captured in this report with the exception of information related to their associated data registries.

As seen on the PHSA Overall Summary Table, total annual grant awards (\$131,522,583) decreased over last year's numbers due to no CFI/BCKDF Infrastructure award competitions in FY 16–17. Total annual grant awards, excluding these large infrastructure awards, have remained relatively stable since FY 2010-11. Of note, during the previous nine years, the majority of award funding has shifted from the government sector to a majority supported by the Non-profit and Industry sectors. This past fiscal year has seen the

lowest percentage of government funding for PHSA agencies at 43.6% from a high of 68.7% in FY 09-10. Conversely over this same time period, the Non-profit sector has gone from a low of 22% of total award funding to a high of 44%. This is recognized as a concern across Canada and has been addressed in the Naylor Report, released in April of 2017, which was commissioned as Canada's Fundamental Science Review by the Canadian Minister of Science. PHSA has been actively involved in advocating, along with entities across Canada, for the implementation of the recommendations resulting from this review. As is evidenced by the increase in the numbers of researchers, researcher trainees, publications, and number of patents issued for FY 16-17, PHSA and its research entities stand poised to benefit from an increase in government funding opportunities as a result of implementation of these recommendations.

The total amount of the Indirect Costs Program (ICP) grant for FY 2016–17 for all PHSA agencies combined was \$4,273,685. This amount is not reported as part of total research funding in this report but is included here as UBC reports this figure to align with the CAUBO (Canadian Association of University Business Officers) policies.

Full reporting on CIHR's new funding scheme begins with this fiscal year. Results from the 09–2015 Foundation Live Pilot #2, the 10-2016 Foundation Grant and the 09–2016 Project Grants for all of Canada and PHSA are favorable. The Foundation Live Pilot #2 was not an open competition and thus reflects success rates within each agency and is not compared to a national average.

Reporting related to Indicator 3: Achieving Economic Benefits and Innovation captured numbers of intellectual property (IP) disclosures and patents at the BC Cancer Agency and BCCH. Data across PHSA agencies remained relatively stable. Of note this year is an increase in issued patents. These include eight issued patents relating to the ARTMS start-up company portfolio which has developed

a new method for generating technetium for imaging scans and 17 issued patents relating to the Essa pharmaceuticals spinoff/start up company which is developing new drugs for the treatment of prostate cancer. Once technologies are licensed, the partner typically funds patent filings in multiple countries. This is especially true for new pharmaceuticals.

For Indicator 4: Advancing Health and Policy Benefits data was collected utilizing an online survey asking respondents to identify any guideline, drug, diagnostic agent or device adopted or approved in FY 2016-17 as a result of research driven by PHSA researchers, or collaborative research in which PHSA researchers were key participants, as well as the benefits resulting from those initiatives. Benefits were classified into two categories (Patient or System Benefit) to more fully summarize the responses. The top three sub-types included Protocols and guidelines, Knowledge dissemination/New policy, and Efficiency, Cost/Benefit or Sustainability. The type of benefit can be found in the third column of the table after each agency section. A key finding for each agency is presented in summary form in the PHSA overall section, with detailed submissions included in the respective agency sections. Further rigor was applied this year in reviewing which outcomes were most aligned with the current definition. Subsequent years will also include the top 3-5 research achievements for each agency. While not intended to be an exhaustive listing, this year's submissions highlight some of the key products resulting from PHSA research that are improving outcomes and system sustainability.

PHSA registries participated in the Registries as Research Resources survey for the fourth year. Of note this year is the inclusion of two new registries (Hereditary Cancer Program and the BC Generations Project). Also identified for the first time this year, but not included in the survey results are the Lung Cancer Screening Program and the Healthy Aging Study.

Clinical trial data is reported using data from the Research Ethics Board (REB) data set and includes principal investigators (PIs) who utilize PHSA facilities and resources but are not formally affiliated with a PHSA research institute and PHSA PIs who utilize a non-PHSA ethics board (ie. UBC's Clinical Research Ethics Board and Behavioral Research Ethics Board). The number of active studies increased by 22 and enrollment increased substantially to 92,366. This

increase is due to one study from Children's & Women's hospital; CLIP [Community Level Interventions for Preeclampsia) Study, which enrolled over 30,000 participants during the fiscal year. Additionally, grant funding type is now being reported for all CT's, using the REB application information as a source, and assists in monitoring the percentage of industry sponsored trials. For detailed definitions of funding types, see glossary, page 85.

Although the data presented in this report provide trending and, in some instances, comparative information, efforts have been made to portray each reporting entity uniquely, to accurately reflect their very different and unique natures. Presented together, they portray the range and depth of research activity associated with PHSA. The unique natures of the research entities result in some variability in the availability and detail of some metrics.

To better understand the metrics reported, it is helpful to refer to the glossary and definitions document (see Appendix 4, pg. 81) that guided data collection.

The following report was prepared with the assistance of the Research Metrics working group comprising representatives of each of the PHSA research entities and PHSA Performance Measurement and Reporting (see Appendix 3, pg. 80). The individuals within this group worked extremely hard to develop consistent definitions and approaches to collecting data which has further strengthened the consistency and clarity of the collected metrics and their efforts are greatly appreciated. The ability to report on all metrics included in the PHSA's research metrics framework is an iterative process and metrics will continue to be refined further in future reports.

### PHSA AGGREGATE ANALYSIS

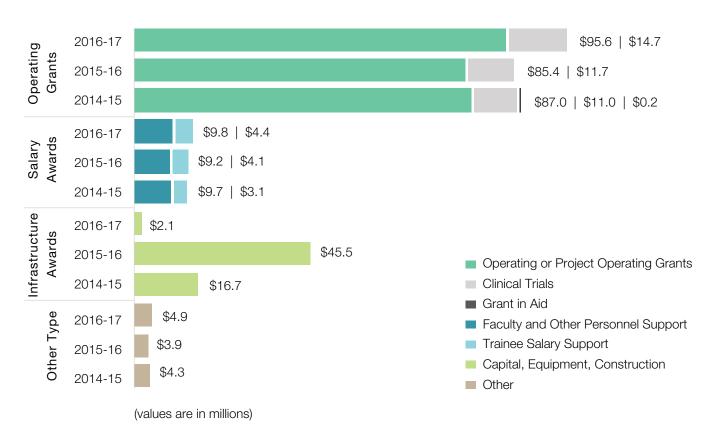
#### **Producing and Advancing Knowledge**

In FY 2016–17, researchers affiliated with PHSA were awarded a total of \$131,522,583 a decrease of approximately \$28 million from FY 2015–16. This reduction is attributed solely to the absence of any major CFI/BCKDF infrastructure grant competitions during the fiscal year. While the total funding decreased, Operating Grants (\$110,287,899) actually increased and had its highest dollar amount since FY 13–14, ending a three-year downward trend. They continue to make up the largest portion (84%) of total funding received. Operating grants support specific, time-limited research projects. While operating grants are the "bread and butter"

of research grants, salary awards are important to provide researchers with the protected time to successfully compete for operating grants and represent approximately 9% of total awards for the past three fiscal years.

A breakdown of funding types and subtypes by fiscal year can be found in Figure 1. For FY 2016–17, the subtype of Operating or Project Operating Grants garnered the largest portion of research funding in its type category. Clinical Trials funding increased by 20% over FY 15–16.

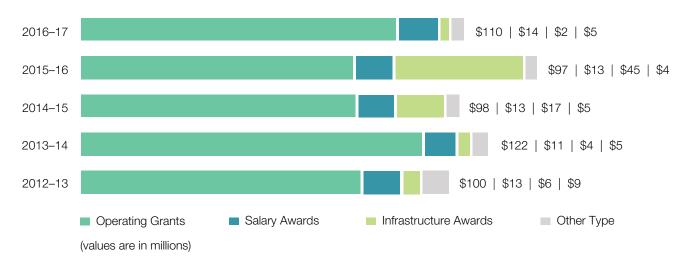
FIGURE 1 Total PHSA Research Funding by Funding Type and Sub-Type by Fiscal Year



Indirect Costs Program grants total \$4,273,685, and represent funding to support the indirect costs of research for tri-council awards, but is not included in total research funding or the figures below. Due to the fact that research support is a shared expense between UBC and PHSA research

agencies, PHSA has negotiated to receive 66% of the applicable UBC ICP grant. Figure 2 shows Total Research Funding by Fiscal Year and Type for the past five fiscal years. Of note is the increase in operating grant awards.

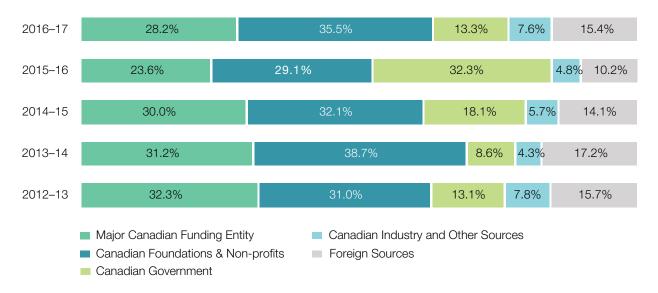
FIGURE 2 Total PHSA Research Funding by Fiscal Year and Type



A comparison of funding source by source category over five (5) fiscal years can be found in Figure 3. This figure, generated by compiling hundreds of potential sources into five categories, highlights the extent to which primary sources of funding vary from year to year. This year, both Canadian Foundations & Non-profits and Major Canadian

Funding entities increased more than 5%. The increase in funding from Major Canadian Funding entities (includes CIHR, NSERC, SSHRC, MSFHR and Genome Canada & Provincial Agencies) has reversed a 4-year downward trend. Canadian Industry and Foreign sources also saw increases at levels reflective of previous fiscal years.

FIGURE 3 Percentage of PHSA Research Funding by Funding Source Category by Fiscal Year



In addition to the above, Figures 4 and 5 show the same award data by RISe sector (see glossary, pg. 85, for sector definition) both by fiscal year and by agency for five fiscal years. Of note on the FY chart, is the jump in the percentage of awards by the Non-profit sector (blue) and the highest percentage of Industry funding attained in five years. Although the reduction in funding from the government sector is reflective of the lack of large infrastructure competitions during the fiscal year it also represents the lowest percentage in the

past 7 years and warrants continued monitoring. A federal review of scientific research funding, released in April 2017, recommended modification to improve the funding apparatus, with no concrete steps taken to date.

Figure 5 shows the percentage of funding by RISe sector and agency for FY 2016–17. This graph reflects the variations in funding sources for all PHSA research entities, as BCMHSUS, BCCDC and WHRI rely heavily on government funding.

FIGURE 4 Percentage of PHSA Research Funding by RISe Sector and Fiscal Year

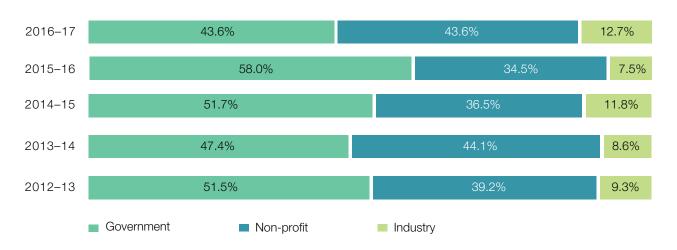
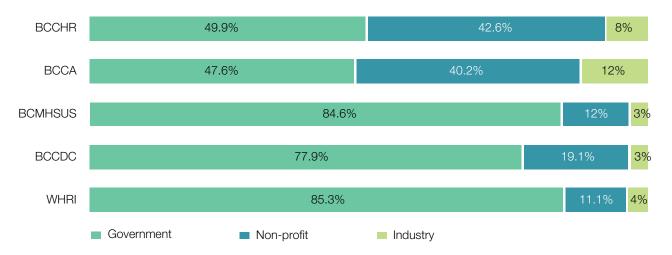


FIGURE 5 Percentage of PHSA Research Funding by RISe Sector and Agency



Now that the new CIHR funding scheme has been phased in, the application success rate is reported for three separate grant opportunities for FY 16–17: 1) The second Foundation Scheme "live pilot" competition, 2) The Oct 2016 Foundation Grant competition, and 3) The Sept 2016 Project Grant

competition. Results (see table 1) are shown for National and PHSA categories. PHSA exceeded the national average for the 2016 Foundation Scheme Open and Project Grant Competitions.

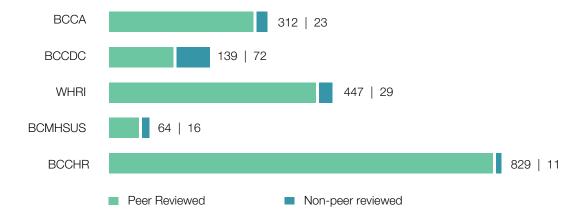
TABLE 1 PHSA Annual Grant Application Success Rate

| Grant Funding Opportunity                  | National Overall Results<br>% (Approved/Submitted) | PHSA Results<br>% (Approved/Submitted) |
|--|--|--|
| Project Grant: Sept 2016                   | 20.7% (596/2884)                                   | 35.6% (26/73)                          |
| Foundation Scheme Live Pilot #2: Sept 2015 | 13.2% (120/910)                                    | 11.5% (3/26)                           |
| Foundation Grant: Oct 2016                 | 12.7% (76/600)                                     | 15% (3/20)                             |

Statistics for publications were collected utilizing SciVal with Scopus as the source. Publications were collected in the categories of books, book chapters, peer-reviewed publications inclusive of published journal articles, case reports, essays, literature reviews, and reports produced for government. See

Figure 6 for a breakdown of total publications by agency and category. Totals are reported by calendar year for all agencies. A breakdown by types is shown in the agency specific sections due to low sample size.

FIGURE 6 Total Number of Publications by Agency and Category



#### **Building Research Capacity**

PHSA research entities identified 810 researchers in categories 1, 2, and 5 in FY 2016–17, up 40.5 from FY 2015–16 (see Figure 7). Category 3 researchers are defined as Affiliate Investigators and represent those researchers with a primary affiliation with a research or academic institution external to PHSA, but who wish to remain collaborators with PHSA researchers. Category 3 researchers totaled 10, a marked reduction from previous fiscal years. PHSA does not track category 3 members funding, publications or trainees. No comparative data is provided this year, as BCCHR adopted new membership categories during FY

16–17. BCCA, BCMHSUS and BCCHR are able to report their researchers utilizing BCCHR newly defined categories, which highlight the amount of time protected for research purposes. BCCDC and WHRI define researchers utilizing a methodology that best reflects the type of work and relationships they have with their researchers. Further information on these methods can be found in specific agency sections. An attempt to count each researcher only once was made by attributing each researcher to the entity where the bulk of salary and/or support are received. Category 1 researchers are best positioned to compete for external grants.

FIGURE 7 Total Number of PHSA Researchers by Category and FY

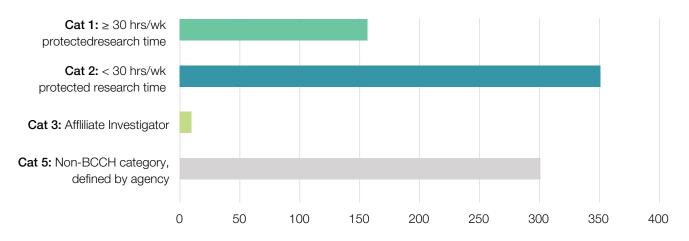


Table 2 provides summary statistics by agency at the Principal Investigator (PI) level. PHSA received funding for 378 Principal Investigators collaborating with 1,271 UBC co-investigators for 1,291 unique studies in FY 2016–17.

This excludes Salary and Other award types as these are not designated for specific studies and the number of co-investigators from other academic institutions.

TABLE 2 Number of Funded Studies, PI's, UBC Co-PI's and Award Amount by Agency

| Agency      | # of Unique Studies | # of Unique PI's<br>by Agency | # of UBC Co-PIs<br>by Agency | Total Award Amount |
|-------------|---------------------|-------------------------------|------------------------------|--------------------|
| BCCA        | 604                 | 168                           | 667                          | \$94,373,181       |
| BCCDC       | 41                  | 23                            | 69                           | \$2,376,395        |
| BCMHSUS     | 15                  | 9                             | 20                           | \$2,055,457        |
| BCCHR       | 595                 | 164                           | 428                          | \$41,052,055       |
| WHRI        | 36                  | 14                            | 87                           | \$2,774,156        |
| Grand Total | 1,291               | 378                           | 1,271                        | \$112,409,461      |

During FY 2016–17, PHSA researchers provided training and supervision to a total of 1,687 research trainees, an increase of 394 or 30% from FY 2015-16. The large increase in FY 16–17 can be attributed to more complete data collection, specifically in the Practicum, Co-op, Honours, and Directed Studies category. This is a significant metric because the training of Post-doctoral fellows (PDFs), Doctoral, and Masters Trainees in particular is a major indicator of the degree to which PHSA and its research entities are

supporting their academic mandate and ensuring the next generation of highly qualified research personnel. In addition, Post-doctoral fellows and Doctorals contribute significantly to the conduct of research under the supervision of principal investigators. While Practicum, Co-op, Honours and Directed Studies students perform less research, providing early trainee opportunities helps cultivate a strong long term workforce. See Figure 8 and 9 for the number of trainees by type and fiscal year for PHSA overall.

FIGURE 8 Total Number of PHSA Trainees by Fiscal Year

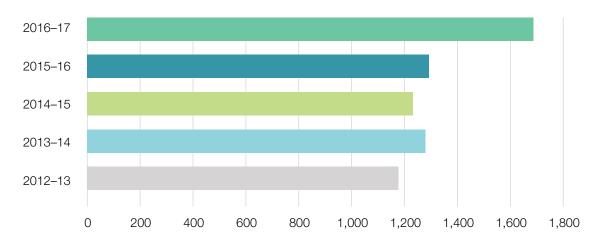
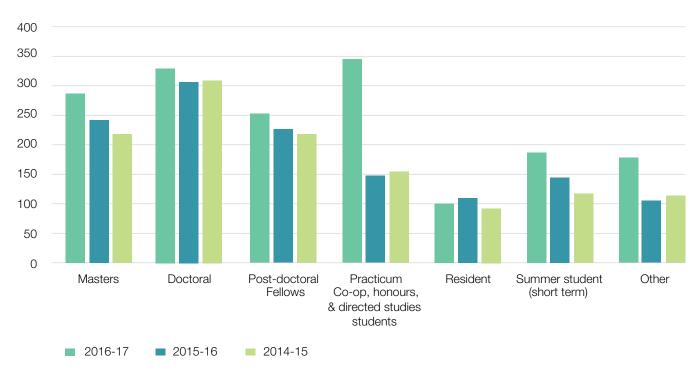


FIGURE 9 Total Number of PHSA Trainees by Type by Fiscal Year



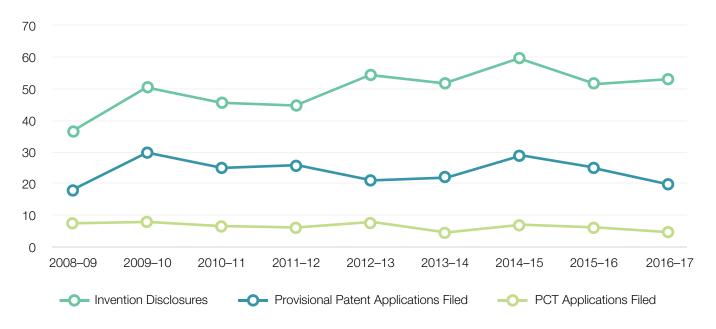
#### **Achieving Economic Benefits and Innovation**

The patent process, along with data on licensing and spinoff companies, is provided to measure the commercialization of discoveries, and other economic benefits resulting from these discoveries. Data are included for BCCA and BCCDC (through the TDO), and BCCHR (through UILO). Agency specific IP related revenue data is provided in agency sections.

See Figure 10 for total number of invention disclosure, provisional patent and patent cooperative treaties (PCT)

applications filed by fiscal year. Invention disclosures are primarily internal BCCA documents, filed with TDO to inform the decision of whether or not to proceed with the patent process. The next stage in the patent process is to file provisional patent applications followed by patent cooperative treaties, or PCTs, which act as a gateway to world-wide patents, each step involving greater specificity.

FIGURE 10 Total # of Invention Disclosures, Provisional Patent and PCT Applications Filed by Fiscal Year



See Figure 11 for the number of national provisional patent applications filed and issued. Applications filed in a given year represent different applications than those which are approved in that same year.

Figure 12 shows all licensing agreements and spin-off companies for both BCCA and BCCHR combined for the past nine years. Agency specific numbers can be found in the agency section. Two spin-off were created at BCCA; Qing Bile Therapeutics and Metera Pharma.

FIGURE 11 Total # of National Provisional Patent Applications Filed and Issued by Fiscal Year

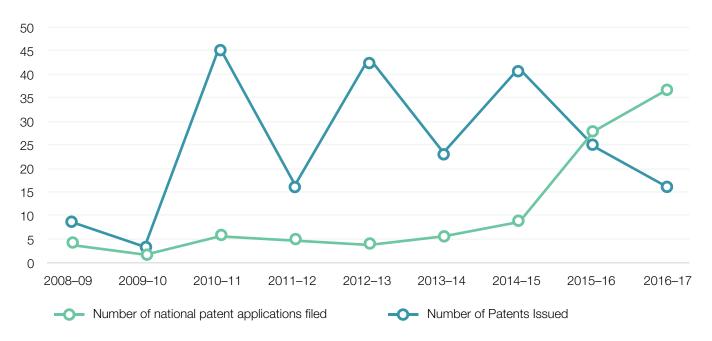


FIGURE 12 License/Assignment Agreements and Spin-Off Companies by Fiscal Year



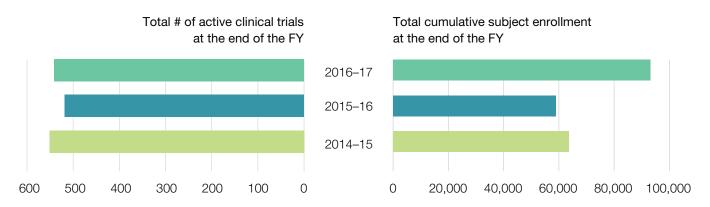
#### **Advancing Health and Policy Benefits**

For FY 2016–17, the number of clinical trials increased by 22 to 541. The large increase in enrollment, is primarily due to enrollment in the CLIP [Community Level Interventions for Pre-eclampsia) Study, which saw a 30,498 increase over last year. See Figure 13 for number of Clinical Trials and Total Cumulative Subject Enrollment by Fiscal Year.

The opportunity to participate in clinical trials is an important metric because it offers patients the opportunity

to participate in clinical evaluation of new drugs, many of which achieve therapeutic benefits beyond those offered by standard of care treatment. Clinical trials also represent the final step in the translational research continuum, which begins with basic or discovery research, includes development of particular products, and culminates with the testing of those products in rigorous trials.

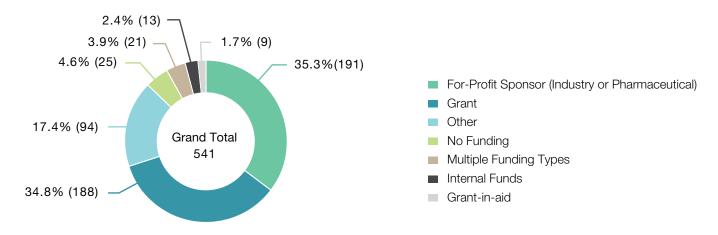
FIGURE 13 Total # of Clinical Trials and Total Cumulative Subject Enrollment by Fiscal Year



For the first time, grant funding type is reported for Clinical Trials. This information is sourced from the REB (Research Ethics Board) file and reflects the funding type entered as part of the ethics application (see glossary, page 85 for a

definition of funding types). This information can be used to trend the percentage of trials that are industry sponsored. See Figure 14 for a breakout of trials by funding type and details on the number of trials in each category.

FIGURE 14 PHSA Percent of Clinical Trial Grant Funding Type: Active and Terminated Trials within the FY

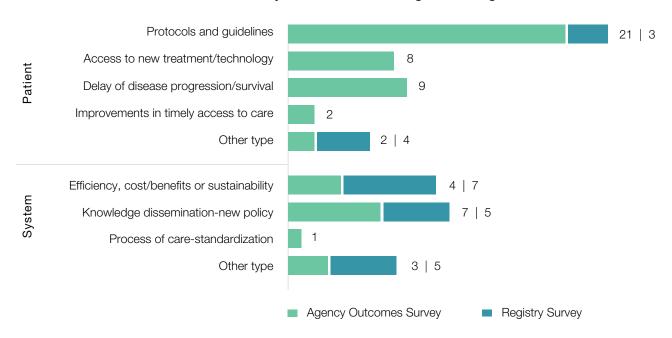


In FY 2016–17, the agencies completed the survey that asked respondents to identify guidelines, drugs, diagnostic agents or devices adopted or approved in FY 2016–17 as a result of research driven by PHSA researchers or collaborative research in which PHSA researchers were key participants. The survey was not intended to be exhaustive, but to capture the significant, top of mind advancements, and, further, asked respondents to identify the benefits to patients, population health, and/or health system sustainability of those advancements.

Respondents were asked to classify the stated benefits into categories to more fully summarize the responses. These

categories are shown below in the third column of data in Table 3 and mirror the benefit categories utilized in the Registry Survey. Figure 15 is a summary of the classification of benefits realized through research at the agencies and with data from the registries, combined. These represent the top choice of category as many benefits were classified into more than one category (see agency sections for details). The other type category includes; used for strategy development, feasibility studies, patient engagement, policy evaluation, securing grant funding, program testing and development of education modules.

FIGURE 15 Classification of Benefits Summary for FY 2016-17 for All Agencies & Registries



In addition, Table 3 lists a key achievement for each agency with full details provided in each agency/reporting entity

section and documents important achievements in translational research.

TABLE 3 Key Agency Achievements—Outcomes Survey

| Please describe any guideline, drug,<br>diagnostic agent or device adopted or<br>approved in 2016/17 as a result of research<br>driven by PHSA researchers.   | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.  | Type of Benefit   |
|---|--|---|
| Research findings and recommendations from a WHRI researcher resulted in a national policy change by Health Canada regarding the regulation of the newly approved drug, Mifepristone, used for the medical termination of pregnancy. This research and advocacy also resulted in two provincial policy changes in British Columbia regarding the regulation and dispensing of Mifepristone.   | Improved outcomes for women due to increased access to treatment for the medical termination of pregnancy. Cost savings to women in British Columbia, who will now have access to free mifepristone at all hospitals, greatly improving rural and remote access to this abortion drug which otherwise may cost women up to \$400 dollars per dose.   | Patient: Access to new treatment or technology System: Efficiency, cost/benefit or sustainability; Knowledge dissemination-new policy   |
| At a time when there was a vacuum of guidance on Zika surveillance, advice and response, BCCDC researchers conducted epidemiological research which led to the formulation of the Zika virus diagnosis, surveillance and follow-up guidelines which resulted in a change in practice.   | These guidelines allowed BC to respond in a nimble fashion to a new epidemic.  | Patient: Protocols and guidelines   |
| BCCA along with Canadian researchers launch Terry Fox PRecision Oncology for Young PeopLE (PROFYLE)   | This program aims for research centres across Canada to come together to provide a platform to molecularly profile the tumours of young Canadian cancer patients.  | Patient: Access to new treatment/technology   |
| BC Children's Hospital investigators created HEARTSMAP, a new online emergency psychosocial assessment and management tool for children and youth in mental health crisis. The tool provides the clinician with guiding questions to collect key information from the patient; it then uses the data to identify areas of need and provide clinicians with recommendations for management. In 2016/2017 HEARTSMAP was implement at nine sites in the Metro Vancouver area and Northern BC. HEARTSMAP was validated and tested at BC Children's. | HEARTSMAP was developed in response to a lack of specialized pediatric mental health care and an increased need for more accurate and consistent assessment of mental health issues in the emergency department (ED), as well as a need for better connections to community resources. HEARTSMAP improves care for children and youth in mental health crisis and supports ED clinicians by equipping them with a standardized, effective approach to assess the mental-health needs of kids. This enables them to provide timely care tailored to the specific needs of each patient. | Patients: Improvements in timely access to care Patients: Protocols and guidelines System: Process of care-standardization System: Efficiency cost/benefits of sustainability |



An agency of the Provincial Health Services Authority

#### **Producing and Advancing Knowledge**

In FY 2016-17, researchers affiliated with BCCA were awarded a total of \$68,513,970.64 in research funding. While this represents a decline from last FY, the amount awarded as Operating Grants (\$62,945,214.22) makes up 92% of total funding received and is an increase of 5% over FY 15-16. The greatest variability in funding type over the past eight years, is with Infrastructure Awards which reached

35% of total awards last year but has been as low as 1.5% in FY 13–14.

A breakdown of funding types and subtypes can be found in Figures 16. BCCA's portion of the Indirect Costs Program grant for FY 2016–17 is \$1,758,491, but is not included in total research funding or the figures below.

FIGURE 16 Total BCCA Research Funding by Funding Type and Sub-type by Fiscal Year

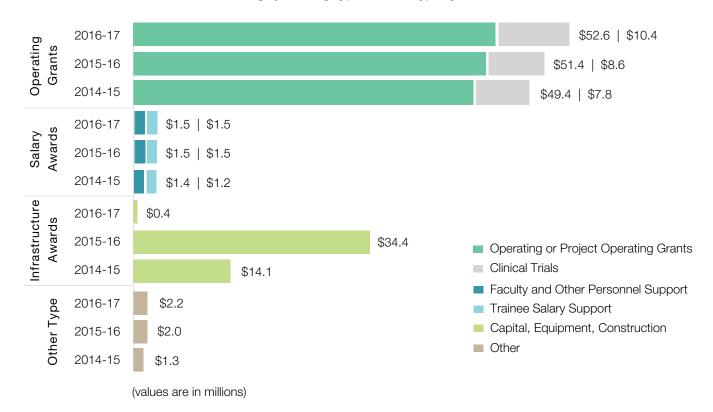
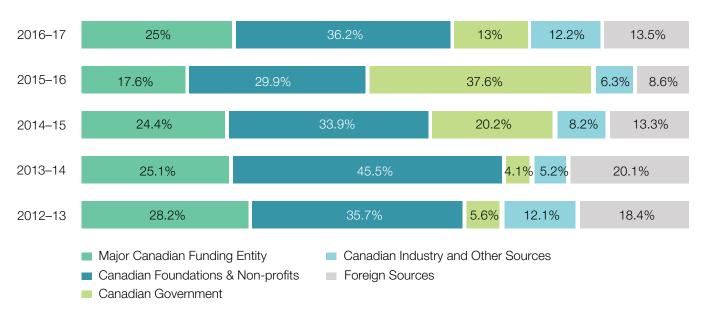


Figure 17 shows the percentage of funding by funding source category for the past 5 fiscal years. The Major Canadian Funding Entity category includes CIHR and its Institutes, Genome Canada and the Provincial Genome Agencies, Michael Smith Foundation for Health Research (MSFHR), Natural Sciences & Engineering Research Council (NSERC), and the Social Sciences & Humanities Research

Council (SSHRC). While there has been fluctuation between categories, Canadian sources of funding have remained approximately 80% of total funding, each year. Of note this FY, is that all categories of funding are at a three year high, with the exception of Canadian Government funding. This is due to the lack of any CFI/BCKDF infrastructure competitions during the FY.

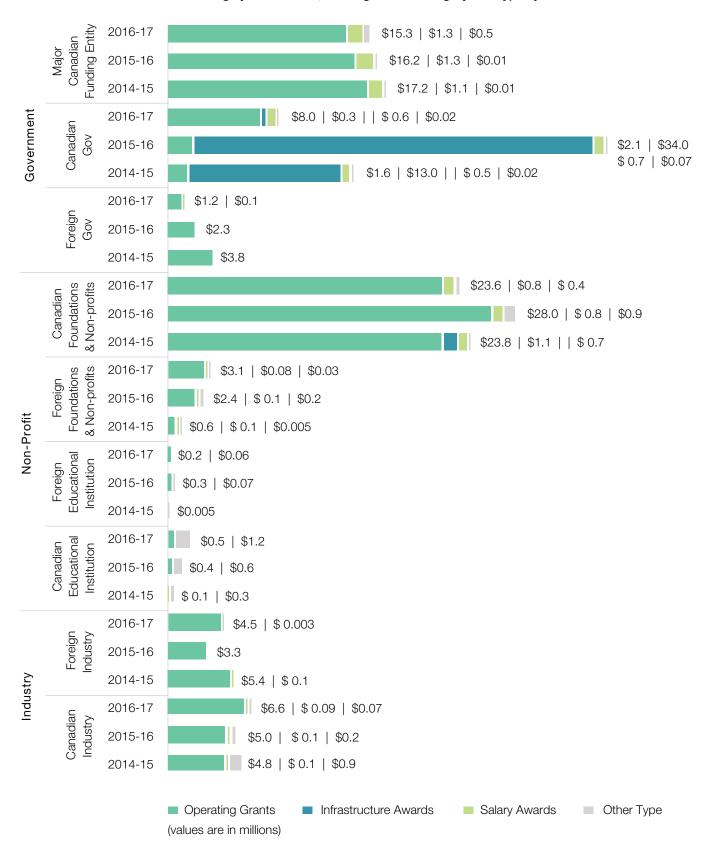
FIGURE 17 Percentage of BCCA Research Funding by Funding Source Category by Fiscal Year



As in the PHSA overall section, BCCA's Total Award Funding is shown by RISe sector, Funding Source Category and Funding Type. In FY 16-17, the top funding sources are Canadian Foundations & Non-profits, Major Canadian

Funding Sources (CIHR, MSFHR, NSERC, SSHRC and Genome Canada) and Canadian Government. Figure 18 details the major funding categories by funding type.

FIGURE 18 BCCA Research Funding by RISe Sector, Funding Source Category and Type by Fiscal Year



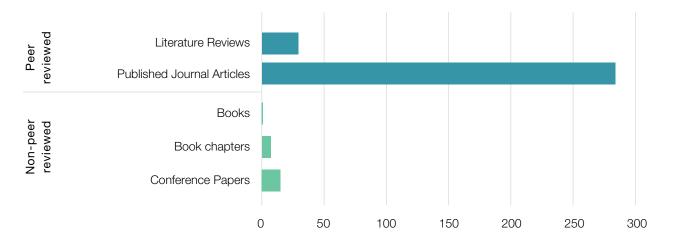
In the first year of reporting under the fully phased in CIHR Funding Scheme, BCCA received approved grants in all three competitions and exceeded national averages for the Project Grant—Sept 2016 and the Foundation Scheme Live Pilot #2—Sept 2015 competitions.

Total number of publications by type and category of peer vs. non-peer review is seen in Figure 19. BCCA had a total of 335 publications, with a majority of published journal articles.

TABLE 4 BCCA Annual Grant Application Success Rate

| Grant Funding Opportunity                  | National Overall Results<br>% (Approved/Submitted) | BCCA Results<br>% (Approved/Submitted) |
|--|--|--|
| Project Grant: Sept 2016                   | 20.7% (596/2884)                                   | 31.8% (7/22)                           |
| Foundation Scheme Live Pilot #2: Sept 2015 | 13.2% (120/910)                                    | 27.3% (3/11)                           |
| Foundation Grant: Oct 2016                 | 12.7% (76/600)                                     | 11.1% (1/9)                            |

FIGURE 19 Total Number of BCCA Publications by Type and Category

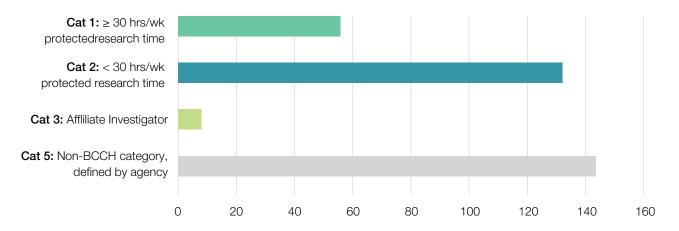


#### **Building Research Capacity**

BCCA has a total of 338 researchers in FY 2016–17 in categories 1, 2, 3 and 5.. While adoption of the BCCHR category classifications is in place, a significant amount (143) of the total researchers are in Category 5, which is an agency specific category used to describe researchers that do not meet BCCHR category classifications. For BCCA, the

majority of Category 5 researchers are Medical or Radiation Oncologists, Program or Practice Leaders, Research Scientists and Nurses. As in past year's reports, researchers whose funding is officially split 50/50 between research entities are classified as 0.5. See Figure 20 for the number of researchers by category.

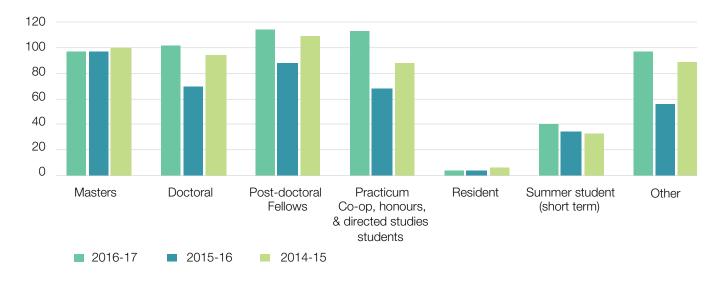
FIGURE 20 Total Number of BCCA Researchers by Category and Fiscal Year



During FY 2016-17, BCCA researchers provided training and supervision to a total of 565 trainees, an increase of 149 attributed to better data collection. See Figure 21 for the number of trainees by type. Factors influencing the number of trainees include but are not limited to, operating

grant success rates; whether trainees can obtain fellowships to secure their own funding, and how often trainee competitions are held and the envelope of funding. Some variability results from the manual data collection process.

FIGURE 21 Total Number of BCCA Trainees by Type and Fiscal Year

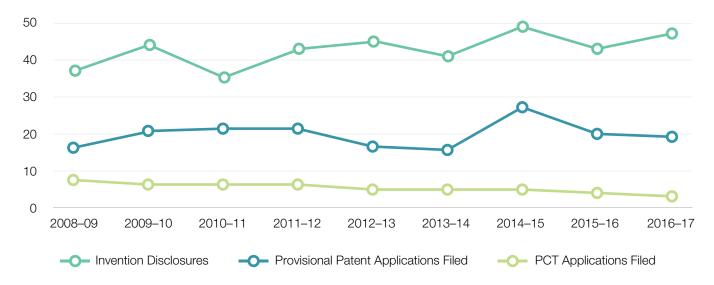


#### **Achieving Economic Benefits and Innovation**

# BCCA Technology Development Office (TDO) Activities

Patent Activity has remained relatively stable over the last nine fiscal years (see Figure 22). Invention disclosures are primarily internal BCCA documents, filed with TDO to inform the decision of whether or not to proceed with the patent process. The next stage in the patent process is to file provisional patent applications followed by patent cooperative treaties, or PCTs, which act as a gateway to world-wide patents.

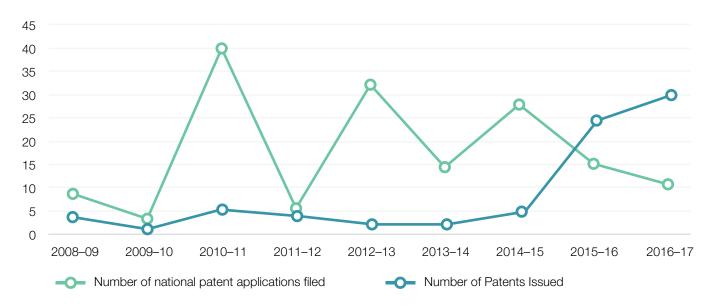
FIGURE 22 BCCA TDO Invention Disclosures, Provisional Patent and PCT Applications by Fiscal Year



National patent applications are then filed with each step involving greater specificity. For a second year, there is a large number of issued patents during the FY. These are the result of eight (8) patents relating to the ARTMS start-up company portfolio which has developed a new method for generating technetrium for imaging scans, and seventeen

(17) patents relating to the Essa pharmaceuticals spinoff/ start-up company which is developing new drugs for the treatment of prostate cancer. Once technologies are licensed, then the partner typically funds patent filings in multiple countries and is especially true for new pharmaceuticals. See Figure 23 for a breakdown by fiscal year.

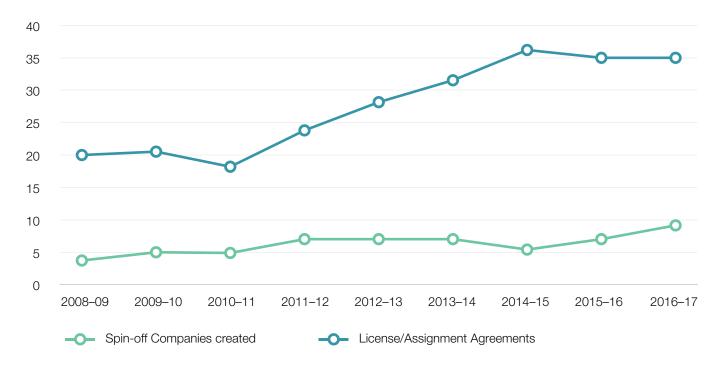
FIGURE 23 BCCA TDO National Patent Activity by Fiscal Year



In FY 2016-17, there were 35 active license agreements (see Figure 24), including one (1) new licenses/assignment agreements. There were two (2) new spin-off companies created; Qing Bile Therapeutics and Metera Pharma. Other active

Spin-off companies include Aquinox Pharmaceuticals, Essa Pharmaceuticals, Repeat Diagnostics, Verisante, Logipath Medical and Fusion Genomics.

FIGURE 24 BCCA License Agreements and Spin-Off Companies by Fiscal Year



IP related revenue, in accordance with UBC (University Industry Liaison Office UILO) definitions (see Glossary: Appendix 4, page 82) is reported in Table 5. Expenses related to patenting, license IP and legal costs totaled \$360,536.24 in FY 2016–17. Realized licensing revenue per the distribution agreements totals \$258,712.91 with \$85,351.64 to

PHSA and \$173,361.27 to BCCA departments. While distribution agreements vary, typically the inventor receives 50% of the net licensing revenue, with the remainder split between PHSA, BCCA departments, and UBC for those researchers with a UBC affiliation.

TABLE 5 TDO IP Related Revenue

| IP Related Revenue              | FY 2013-14   | FY 2014–15     | FY 2015-16     | FY 2016–17     |
|---------------------------------|--------------|----------------|----------------|----------------|
| Royalties                       | \$387,894.13 | \$731,038.63   | \$337,646.78   | \$765,483.79   |
| Equity Liquidated               |              | \$37,032.37    | \$257,794.00   | \$101,351.28   |
| License Fees                    | \$54,725.00  | \$200,740.00   | \$111,500.00   | \$149,840.95   |
| License Management              | \$314,161.97 | \$358,490.88   | \$299,798.18   | \$237,120.85   |
| Option Fees                     |              |                | \$5,000.00     |                |
| Technology Assignment           |              |                |                |                |
| Gross Licensing Revenue (total) | \$756,781.10 | \$1,327,301.88 | \$1,011,738.96 | \$1,253,796.85 |

#### **Advancing Health and Policy Benefits**

See Table 6 for a detailed breakdown of clinical trial activity by fiscal year. Of note, is that approximately 21% of BCCA trials had no enrollment figures in the REB applications, an improvement over the 24% figure from FY 2015–16. Once these fields are made mandatory as opposed to optional, enrollment figures should increase.

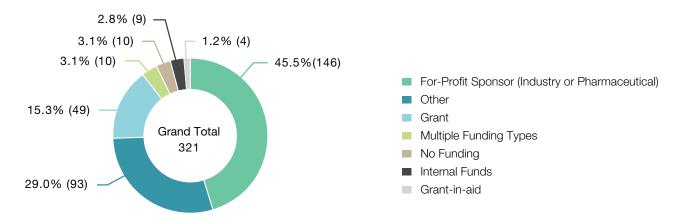
**TABLE 6** BCCA Clinical Trials

|  | 11–12  | 12–13  | 13–14  | 14–15  | 15–16  | 16–17  |
|--|--------|--------|--------|--------|--------|--------|
| Total Number of Clinical Trials active during the FY         | 272    | 300    | 321    | 317    | 303    | 321    |
| Status of the Trial at the end of the FY:                    |        |        |        |        |        |        |
| Total Number of Active Trials                                | 151    | 212    | 274    | 234    | 249    | 265    |
| Total Number of Trials that closed during the FY             | 121    | 88     | 47     | 83     | 54     | 56     |
| Enrolment Numbers:   |        |        |        |        |        |        |
| Expected Local Subject Enrolment (for the term of the study) | 36,022 | 35,899 | 36,653 | 41,867 | 41,598 | 44,305 |
| Total Cumulative Subject enrolment at the end of the FY      | 24,439 | 25,515 | 27,299 | 28,521 | 29,244 | 30,084 |

For the first time, grant funding type is reported for Clinical Trials. This information is sourced from the REB file and reflects the funding type entered as part of the ethics application (see Glossary, page 85 for a definition of funding types). This information can be used to trend the percentage of trials that are industry sponsored. Forty-six percent (46%) of BCCA Clinical Trials are Industry funded. See Figure 25 for a breakout of trials by funding type.

The following Table 7 reflects a sample of key guidelines, drugs, diagnostic agents or devices adopted or approved in FY 2016–17 as a result of research driven by BCCA researchers, and their corresponding benefits. These outcomes represent important achievements in translational research that are improving patient outcomes and system sustainability.

FIGURE 25 BCCA Percentage of Clinical Trial Grant Funding Type: Active and Terminated Trials within the FY



**TABLE 7** BCCA Outcomes Survey Responses

| Please describe any guideline, drug, diagnostic agent or device adopted or approved in 2016/17 as a result of research driven by PHSA researchers. | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.  | Type of Benefit                             |
|--|--|---|
| BCCA researchers develop ProMisE, an endometrial cancer classifier   | The ProMisE model represents a cost-effective assay that can be implemented in a clinical setting to improve the categorization and risk stratification of endometrial cancer. | Patient: Access to new treatment/technology |
| BCCA along with Canadian researchers launch Terry Fox PRecision Oncology for Young PeopLE (PROFYLE)  | This program aims for research centres across Canada to come together to provide a platform to molecularly profile the tumours of young Canadian cancer patients.              | Patient: Access to new treatment/technology |
| Researchers from UBC, BCCA and University of Montreal developed droplet multiple displacement amplification (MDA) for single cell analysis         | MDA is a method that uses commercially available liquid dispensing to perform high-throughput single-cell MDA in nanoliter volumes.  | System: Other type                          |

| Please describe any guideline, drug, diagnostic agent or device adopted or approved in 2016/17 as a result of research driven by PHSA researchers.                     | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.   | Type of Benefit   |
|--|---|---|
| Device: New software program for improving clinical flow cytometry-based diagnostic and disease monitoring procedures using an in house automated data analysis system | Established multiple collaborations with external clinical and commercial groups to begin implementation/adoption phase: (i) Collaboration with Providence Health care in Portland OR, USA for use of this software in their clinical trials. (ii) Collaboration with Anixa Diagnostics Inc. to incorporate this software into their clinical trial pipelines. (iii) Collaboration with the Canadian National Transplant Research Program for use of this software in their patient monitoring studies.   | Process of care – protocol implementation; Efficiency, cost benefits or sustainability; Resource improvements: workforce  |
| Diagnostic agent: Establishment of a 15-parameter flow cytometry assay for routine clinical assessment of lymphoproliferative disorders.                               | Collaboration between the Research and Clinical Flow Cytometry Laboratories at the BCCA has enabled the development, validation, and successful implementation of this 15-parameter assay. This is the most technologically sophisticated clinical assay of its type in routine clinical use in North America, and likely also in Europe as well. Within minutes, it offers unparalleled diagnostic accuracy due to its ability to collect data on multiple features of millions of cells assessed individually with high sensitivity and precision. This assay went live in November, 2015 and is now performed routinely on every clinical sample submitted to BCCA for flow cytometric analysis. Technological improvements and optimization of workflow and resource utilization made in the past year at BCCA, now allow this procedure to be performed more cheaply than less sensitive assays still used in most other clinical flow cytometry laboratories. | Delay of disease; Access to new treatments; Protocols and guidelines; Improvement in timely access to care; Process of care: standardization; Process of care: protocol implementation; Efficiency, cost benefits or sustainability; Resource improvements: workforce |
| The work done at the BC Cancer Agency has led to the recognition of 2 subtypes of DLBCL in the revised WHO definition of lymphoid neoplasms                            | Superior classification of DLBCL will lead to improved research into pathogenesis, targeted treatments and outcomes.  | Patient: Protocols and guidelines   |
| The work done on MYC and BCL2 translocations in DLBCL have led to a new entity in the revised 2016 WHO classification of lymphoid neoplasms                            | Recognition and study of this new entity will have a major impact on clinical trial design and specific focus on this patient population that currently have poor outcomes.   | Patient: Protocols and guidelines   |
| Development of a deliberative public engagement methods and evidence for COAC and CAPCA  | A pan-Canadian study ran a set of deliberative public engagement events to help inform drug funding decision making for all of Canada. The final report is being directly used as an advisory paper by CAPCA and CPAC.  | System: Efficiency, Cost/<br>benefits or sustainability   |
| Development of an ongoing framework for patient and public engagement concerning drug funding decision-making  | Working directly with CAPCA on patient and public engagement, and also on development of a pan-Canadian approach to cancer drug funding decisions. A recent report, A qualitative evaluation of the pCODR patient engagement process, is currently used by CAPCA as an advisory paper.  | System: Efficiency, Cost/<br>benefits or sustainability   |
| Economic Analysis of cost-effectiveness of a new genetic panel for AML developed by a BCCA Researcher  | Economic analysis was used to inform the decision to prvide the new test. New test is now in place for AML patients in BC.  | Patient: access to new treatment/technology   |

| Please describe any guideline, drug, diagnostic agent or device adopted or approved in 2016/17 as a result of research driven by PHSA researchers.   | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.   | Type of Benefit   |
|--|---|---|
| Economic analysis of lung cancer screening for high-risk individuals   | Economic analysis was used to develop a business case for the MoH. Lung cancer screening for high-risk people will be funded for all eligible BC residents.   | Patient: Access to new treatment/technology             |
| Cost effectiveness of genomic diagnostics in acute myeloid leukemia  | This evidence was used in the decision to fund the use of the diagnostic in patient care in BC, resulting in quality and quantify of life gains for patients.   | System: Efficiency, Cost/<br>benefits or sustainability |
| Cancer dialogues documentary   | This documentary was produced to engage the Canadian public on the evidence needed and trade-off's of funding high-cost cancer drugs. It was used in a series of public engagement events (5 provincial and 1 national) held across Canada engaging 120 sampled members of the public. The documentary can be found on the CCSR, ARCC and CPAC websites http://cc-arcc.ca/societal-values-and-public-engagement-2/. Further, based on these results, public engagement deliberative events are being considered for funding on a rolling basis across Canada. | System: Efficiency, Cost/<br>benefits or sustainability |
| New IP protecting a formulation method for metal based therapeutics was submitted to the EPO   | This technology has enabled the development of a novel class of therapeutics. The technology was acquired by Cuprous.   | Patient: Other type                                     |
| BC Cancer Agency staff were members of an investigative team working on a program that focuses on healthy eating, active living (physical activity) and mental wellness.  The POWERPLAY program is a gendersensitive workplace health promotion program for male-dominated worksites | Improved men's health focusing on modifiable lifestyle behaviours to prevent cancer and other chronic disease.  | Patient: Other type                                     |



#### **Producing and Advancing Knowledge**

In FY 2016-17, researchers affiliated with BCCHR were awarded a total of \$55,172,149.45 in research funding, an increase of \$3,309,283 (6%) over last FY. The amounts awarded as Operating Grants (\$41,149,046) make up approximately 75% of total funding received and represent

a 28% increase over last FY. A breakdown of funding types and subtypes can be found in Figure 26.

BCCHR's portion of the Indirect Costs Program grant totaled \$2,086,207, for FY 2016-17 but is not included in total research funding or the figures below.

FIGURE 26 Total BCCHR Research Funding by Funding Type and Sub-type by Fiscal Year

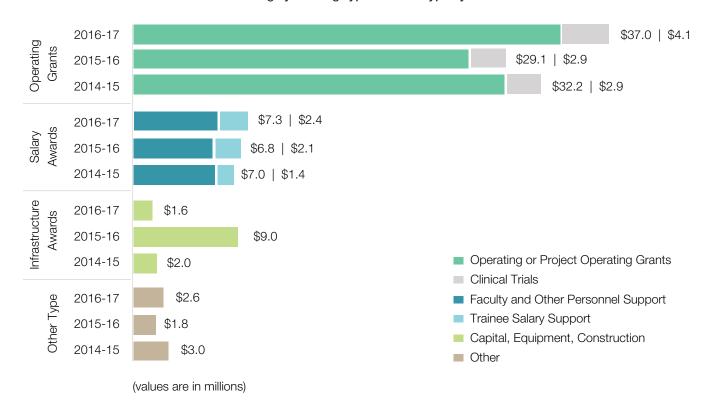


Figure 27 shows funding by funding source category. Of note is the over 8% increase in funding from Canadian Foundations & Non-profits as well as an increase of 5.5% in Foreign Sources.

The top three funding categories are Canadian Foundations & Non-Profits (39%) and increase of 9% over last FY, Major Canadian Funding Entity (28%) a drop of 10%, and Canadian Government (12%). Figure 28 details the RISe sector and funding categories by funding type.

FIGURE 27 Percentage of BCCHR Research Funding by Funding Source Category by Fiscal Year

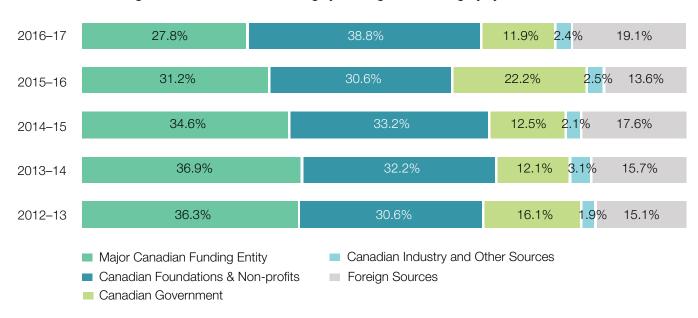
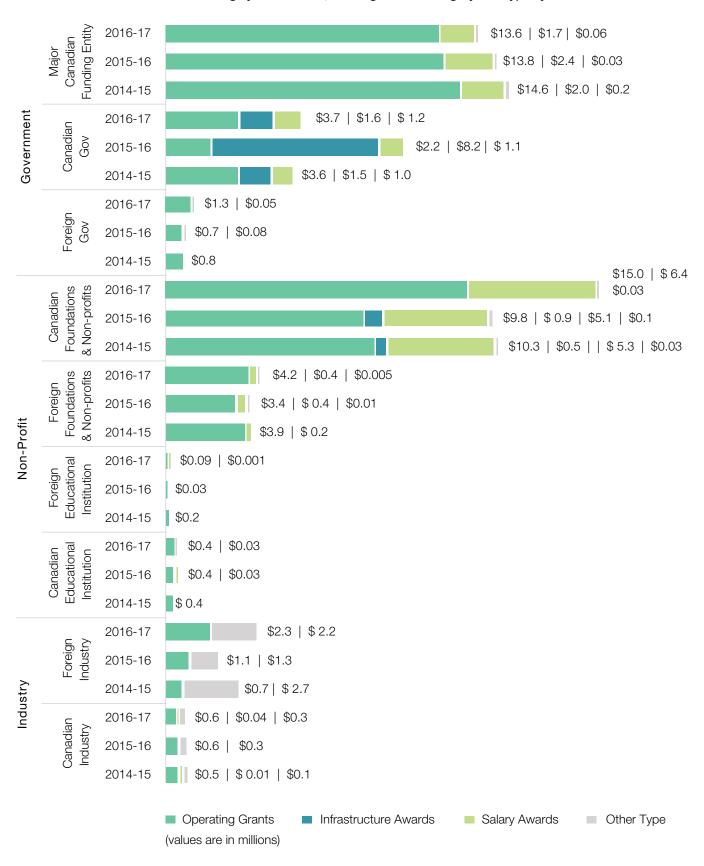


FIGURE 28 BCCHR Research Funding by RISe Sector, Funding Source Category and Type by Fiscal Year



BCCHR exceeded the national average in the CIHR open grant competitions for the September 2016 Project grant and for the October 2016 Foundation Grant (see table 8).

They had no approved applications in the September 2015 Foundation Live Pilot competition.

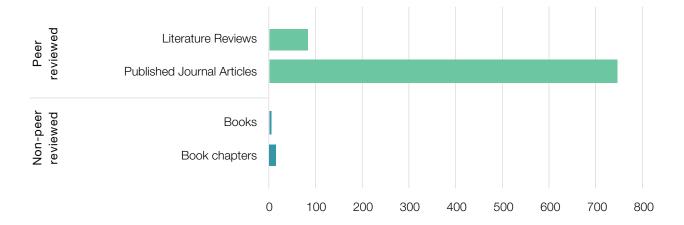
TABLE 8 BCCHR Annual Grant Application Success Rate

| Grant Funding Opportunity                  | National Overall Results<br>% (Approved/Submitted) | BCCHR Results<br>% (Approved/Submitted) |
|--|--|---|
| Project Grant: Sept 2016                   | 20.7% (596/2884)                                   | 27.4% (14/51)                           |
| Foundation Scheme Live Pilot #2: Sept 2015 | 13.2% (120/910)                                    | 0% (0/15)                               |
| Foundation Grant: Oct 2016                 | 12.7% (76/600)                                     | 66.6% (2/3)                             |

BCCHR had 840 publications in calendar year 2016, with 99% of them being peer reviewed. Total number of publications by type and category of peer vs. non-peer reviewed, is seen in Figure 29. Peer review represents the gold standard for scientific credibility. The agency total represents the number of publications where at least one agency

researcher was an author of the publication. When researchers from more than one research entity/agency collaborate on the same publication, it is counted once for each agency. BCCHR includes case reports and essays in journal articles and accepts e-journal articles.

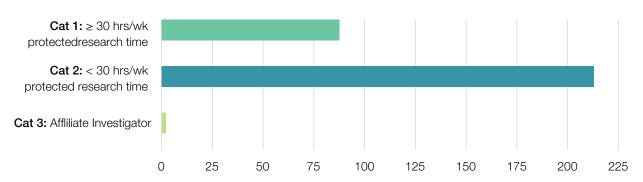
FIGURE 29 Total Number of BCCHR Publications by Type and Category



#### **Building Research Capacity**

In June of 2016, BCCHR formally launched a new membership program for all members of the Oak Street community who participate in or have an interest in research. This program is inclusive of all researchers on the site, with no funding requirements or designated research time required to apply to be an investigator. BCCHR has a total of 304 researchers in categories 1–3. The distribution of these researchers is represented in Figure 30. Researchers in categories 1–3 are primarily based on the Children's & Women's Health Centre of BC campus with the largest proportion of the members being split between Category 1—those that have greater than 30 hours per week of their time protected for research and Category 2—those that have less than 30 hours per week of protected research time. Category 3 members (2 in FY 2016–17) are affiliate investigators that are not based on site but who collaborate with BCCHRI members and are affiliated with a research theme. Their primary affiliation will be with another academic and/or research institution. The purpose of this category is to provide official recognition for these individuals who collaborate with BCCHR members on a regular basis. The BCCHR does not track category 3 members funding, publications or trainees. There is one additional category, Emeritus/Emerita Investigators who has prior status as an investigator with BCCHR.

FIGURE 30 Total Number of BCCHR Researchers by Category



During FY 2016–17, BCCHR researchers provided training and supervision to a total of 530 (up 159 from FY 2015–16) trainees. This increase was due to better data collection and definition of specific categories. See Figure 31 for number of

trainees by type. BCCHR currently tracks full-time research trainees (masters, doctoral and postdoctoral fellows) and summer students undertaking their training at BCCHR.

160 140 120 100 80 60 40 20 0 Masters Doctoral Post-doctoral Practicum, Resident Summer student Co-op, honours Fellows (short term) & directed studies students 2016-17 2015-16 2014-15

FIGURE 31 Total Number of BCCHR Trainees by Type

# **Achieving Economic Benefits and Innovation**

The number of invention disclosures, provisional patent and PCT applications filed by fiscal year are shown in Figure 32.

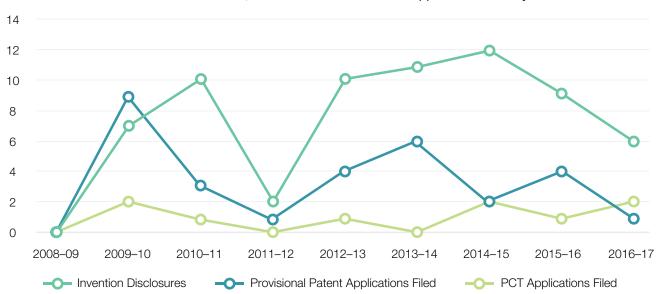
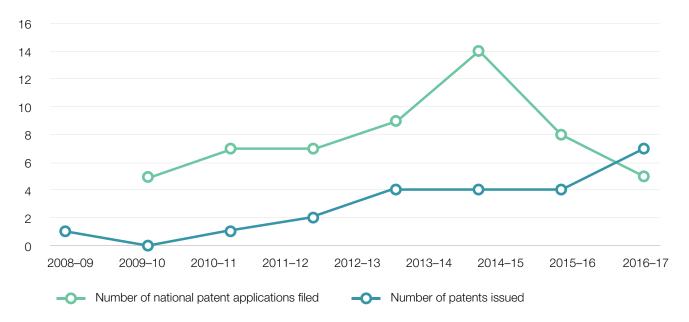


FIGURE 32 BCCHR Invention Disclosures, Provisional Patent and PCT Applications Filed by Fiscal Year

Patents are reported in Figure 33 below. Applications filed in a given year represent different applications than those which are approved in that same year (which typically are

the result of applications in previous years). Data is collected and reported by the University of British Columbia University-Industry Liaison Office (UILO).

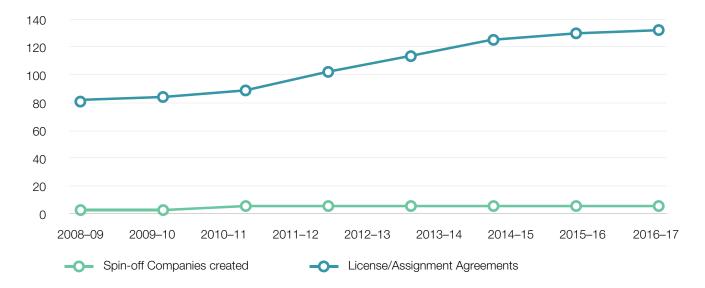
FIGURE 33 BCCHR National Patent Activity by Fiscal Year



In FY 2016-17 there were 132 (up by 4) active license/assignment agreements in place (See Figure 34). No new spin-off companies have been created. BCCHR holds shares in three active companies—Urodynamix Technologies (publicly

traded), Lions Gate Technologies, and BCY Lifesciences (publicly traded). Xenon Pharmaceuticals (private) is held in trust by UBC so is not included in the totals below.

FIGURE 34 BCCHR License/Assignment Agreements and Spin-off Companies by Fiscal Year



See Table 9 for BCCHR data by fiscal year. BCCHR reported indirect expenses for patenting, legal & related

costs of \$68,900 for FY 2016-17. Realized revenue per the distribution agreements for FY 2016-17 was \$23,665.

TABLE 9 BCCHR IP Related Revenue

| IP Related Revenue            | FY 2013–14  | FY 2014-15 | FY 2015–16   | FY 2016–17 |
|-------------------------------|-------------|------------|--------------|------------|
| Royalties                     | \$55,375.30 | \$211,800  | \$178,795.65 | \$258,100  |
| Equity Liquidated             |             |            |              |            |
| License Fees                  |             |            |              |            |
| License Management            |             | \$65,800   |              | \$36,600   |
| Option Fees                   |             |            |              |            |
| Technology Assignment         |             |            |              |            |
| Net Licensing Revenue (total) | \$55,375.30 | \$149,900  | \$178,795.65 | \$225,800  |

#### **Advancing Health and Policy Benefits**

See Table 10 for a detailed breakdown of clinical trial activity by fiscal year. Of note is that approximately 26% of BCCHR trials had no enrollment figures as compared to 23% last fiscal year. The large increase in enrollment, is primarily due

to enrollment in the CLIP [Community Level Interventions for Pre-eclampsia) Study, which saw a 30,498 increase over last year. Once these fields are made mandatory as opposed too optional, enrollment figures should increase.

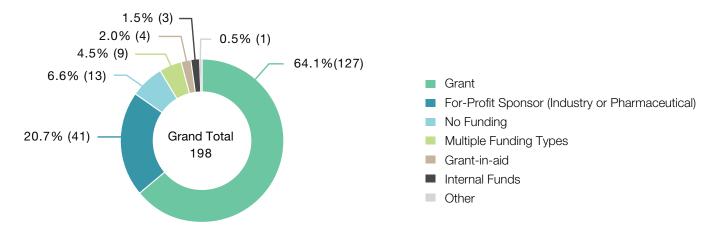
**TABLE 10** BCCHR Clinical Trials

|  | 11–12 | 12–13  | 13–14   | 14–15   | 15–16   | 16–17   |
|--|-------|--------|---------|---------|---------|---------|
| Total Number of Clinical Trials active during the FY         | 146   | 154    | 166     | 183     | 180     | 198     |
| Status of the Trial at the end of the FY:                    |       |        |         |         |         |         |
| Total Number of Active Trials                                | 80    | 101    | 133     | 143     | 152     | 154     |
| Total Number of Trials that closed during the FY             | 66    | 53     | 33      | 40      | 28      | 44      |
| Enrolment Numbers:   |       |        |         |         |         |         |
| Expected Local Subject Enrolment (for the term of the study) | 9,285 | 10,037 | 120,491 | 102,505 | 103,936 | 106,212 |
| Total Cumulative Subject enrolment at the end of the FY      | 2,191 | 1,851  | 7,023   | 31,379  | 26,846  | 57,789  |

For the first time, grant funding type is reported for Clinical Trials. This information is sourced from the REB (Research Ethics Board) file and reflects the funding type entered as part of the ethics application (see glossary, page 85 for a

definition of funding types). Sixty-four percent (64%) of BCCHR's Clinical Trials are Grant funded, with only 21% Industry funded. See Figure 35 for a breakout of trials by funding type.

FIGURE 35 BCCHR's Percentage of Clinical Trial Grant Funding Type: Active and Terminated Trials within the FY



The following table 11 reflects a sample of key guidelines, drugs, diagnostic agents or devices adopted or approved in FY 2016-17 as a result of research driven by BCCHR researchers, and their corresponding benefits. These

outcomes represent important achievements in translational research that are improving patient outcomes and system sustainability.

**TABLE 11 BCCHR Outcomes Survey Responses** 

| Please describe any guideline, drug, diagnostic agent or device adopted or approved in 2016/17 as a result of research driven by PHSA researchers.  | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.  | Type of Benefit   |
|---|--|---|
| BC Children's Hospital investigators created HEARTSMAP, a new online emergency psychosocial assessment and management tool for children and youth in mental health crisis. The tool provides the clinician with guiding questions to collect key information from the patient; it then uses the data to identify areas of need and provide clinicians with recommendations for management. In 2016/2017 HEARTSMAP was implement at nine sites in the Metro Vancouver area and Northern BC. HEARTSMAP was validated and tested at BC Children's. | HEARTSMAP was developed in response to a lack of specialized pediatric mental health care and an increased need for more accurate and consistent assessment of mental health issues in the emergency department (ED), as well as a need for better connections to community resources. HEARTSMAP improves care for children and youth in mental health crisis and supports ED clinicians by equipping them with a standardized, effective approach to assess the mental-health needs of kids. This enables them to provide timely care tailored to the specific needs of each patient. | Patients: Improvements in timely access to care Patients: Protocols and guidelines System: Process of care-standardization System: Efficiency cost/benefits of sustainability |

| Please describe any guideline, drug, diagnostic agent or device adopted or approved in 2016/17 as a result of research driven by PHSA researchers.  | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.  | Type of Benefit   |
|---|--|---|
| An expert panel organized by the U.S. government has recommended that most infants should eat peanut-based food by the time they are six months old. A BC Children's Hospital investigator was invited to take part in the panel because of his previous research surveying health professionals on when and how they recommend peanut introduction, as well as his contributions to earlier guidelines and communiques from Canadian and worldwide professional groups. The expert panel's guidelines were published in the Journal of Allergy and Clinical Immunology and Allergy, Asthma and Clinical Immunology.  | Peanut allergies are among the most common food allergies in Canada, affecting about two in every 100 children in the country. Early exposure to peanuts is believed to reduce the incidence of lifethreatening allergies.   | Patient: Protocols and guidelines System: Knowledge dissemination-new policy                        |
| Researchers with BC Children's Hospital and the BC Women's Health Research Institute developed SmartMom, Canada's first prenatal education program delivered by text message. SmartMom was piloted in a small community before launching throughout Northern Health. SmartMom delivers timely, targeted information to users based on their gestational age and individual interest in reducing smoking, drugs or alcohol. Text messages include prenatal health information aligned with professional practice standards, and links to evidence-based web sources and local community resources.   | SmartMom transforms prenatal education from the classroom model to a format that meets the needs not only of the younger, mobile phone-friendly generation, but also those located in rural and remote communities. SmartMom increases access to health information, health resources, and motivates health-related behaviour change throughout pregnancy.   | Patient: Access to<br>new treatment/technology<br>System: Knowledge<br>dissemination                |
| The World Health Organization (WHO) adopted a resolution to implement a global action plan to improve the prevention, diagnosis, and management of sepsis at the WHO 2017 World Health Assembly. Clinicians and investigators with the Centre for International Child Health at BC Children's Hospital, directly contributed to the creation of this resolution. They also informed and supported it through the publication of over 40 articles on sepsis; international leadership with advocacy and lobby groups; support for the founding of groups such as the Global Sepsis Alliance, World Sepsis Day and the Sepsis Initiative - World Federation of Pediatric Intensive & Critical Care Societies; and speaking at over 10 international meetings. | Worldwide, sepsis causes approximately six million deaths every year. Most of these deaths are preventable and occur in lower middle-income countries. The adoption of this resolution enables the WHO Secretariat to collaborate with other organizations in the United Nations (UN) systems. It also allows UN partners to commit resources that enhance access to quality, safe, effective and affordable types of treatments for sepsis. | Patients: Delay of disease progression/survival System: Efficiency, cost/benefits or sustainability |
| Researchers with BC Children's Hospital's Centre for International Child Health led the development of guidelines for pediatric sepsis and septic shock management in resource-limited settings released by the Global Intensive Care Working Group with the European Society of Intensive Care Medicine.   | The guidelines provide direction on how pediatric septic shock should be identified and treated in intensive care units in resource-limited settings. The goal is to improve mortality and morbidity outcomes for the millions of children treated for sepsis in facilities lacking in laboratory support, equipment and trained staff.  | Patient: Protocols and guidelines   |

| Please describe any guideline, drug, diagnostic agent or device adopted or approved in 2016/17 as a result of research driven by PHSA researchers.  | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.   | Type of Benefit   |
|---|---|---|
| Investigators with the Centre for International Child Health at BC Children's Hospital were part of the Canadian team whose research informed the guidelines for supportive care for Ebola. Funded by the Canadian Institutes of Health Research and organized with the World Health Organization, these guidelines defined best practices for generic interventions – such as patient monitoring and fluid management.   | These guidelines will be the standard of care for global organizations during future Ebola outbreaks.   | System: Knowledge<br>dissemination-new policy   |
| In May 2016, the Canadian Paediatric Society updated its position statement: Preventing Hospitalizations for Respiratory Syncytial Virus (RSV) to align with evidence-based guidelines issued by the BC RSV Immunoprophylaxis Program at BC Children's Hospital. These guidelines were based on research from BC Children's showing that three to four doses of the preventative drug palivizumab may protect at-risk infants from RSV as effectively as the previous recommendation of five doses.   | RSV is a common virus that infects the lungs and respiratory tract, and can lead to life-threatening illness in vulnerable infants. These guidelines reduce the need for injections in babies, preventing unnecessary pain and reducing the total number of hospital visits. The BC RSV Immunoprophylaxis Program saves approximately \$2 million a year with its reduced dose program, and it is estimated that the per capita cost in BC is about \$31 compared to the national per capita cost of \$114. This research was funded through external grants and the BC RSV Immunoprophylaxis Program's own quality assurance activities. | Patient: Protocols and guidelines System: Efficiency, cost/benefits or sustainability     |
| In May 2016, BC Women's Hospital + Health Centre launched the first clinical screening program for CMV in Canada. Under this new program, all babies who fail the newborn hearing test or who are in the neonatal intensive care unit will be screened for CMV. This new program came out of research from BC Children's Hospital that showed CMV infection is underdiagnosed in BC and was developed through a collaboration between the BC Early Hearing Program, BC Children's and BC Women's.   | CMV is a common virus that can spread from mothers to fetuses during pregnancy and result in serious health problems in children. Early diagnosis of babies with CMV enables early intervention and can reduce lifelong health impacts, including hearing loss and developmental delay.   | Patient: Delay of disease progression/survival System: Knowledge dissemination-new policy |
| The Province of Ontario has announced that they will begin universal newborn congenital cytomegalovirus (CMV) screening in 2018. This expansion of the province's existing newborn screening program is based, in part, on studies led by BC Children's Hospital investigators showing that CMV infection is underdiagnosed in BC and that screening newborn babies for CMV infection is cost-effective and helps prevent lifelong disabilities.  | CMV is a common virus that can spread from mothers to fetuses during pregnancy and result in serious health problems in children. Early diagnosis of babies with CMV enables early intervention and can reduce lifelong health impacts, including hearing loss and developmental delay.   | Patient: Delay of disease progression/survival System: Knowledge dissemination-new policy |
| Researchers with the Centre for International Child Health at BC Children's Hospital have developed an intervention that can be used in under-resourced settings to improve care and support for children under five who were discharged from hospital after a serious infection. Smart Discharges uses low-cost mobile pulse oximetry sensors developed by BC Children's Hospital researchers. Researchers are currently working with hospitals in Uganda to validate Smart Dischargers and with the Ugandan Ministry of Health to develop the required policies to expand throughout the country. | Children under five hospitalized for serious infections (sepsis) in Uganda have a very high post-discharge mortality rate. As many die in the months after they leave the hospital as during hospitalization — five per cent in each case. Smart Discharges helps health care workers precisely and efficiently allocate resources, making it easy and cost-effective to encourage healthy behaviours and prevent deaths of vulnerable children. Preliminary results show that Smart Discharges improves detection of illness after discharge and may also lead to a 30% reduction in post-discharge mortality.                           | Patient: Access to new treatment/technology   |

| Please describe any guideline, drug, diagnostic agent or device adopted or approved in 2016/17 as a result of research driven by PHSA researchers.   | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.  | Type of Benefit                               |
|--|--|---|
| OutsidePlay.ca is a new online risk reframing tool developed by researchers with the BC Injury Research and Prevention Unit (BCIRPU) at BC Children's Hospital. This tool helps parents of young children learn the importance of outdoor risky play and develop strategies for letting their children engage in healthy outdoor play. Since its launch in February 2017, over 7,000 unique visitors have visited the site. This new tool was informed by a wide-range of research from the BCIRPU including a recent study in <i>Health and Quality of Life Outcomes</i> that found within four months of an injury, most children have recuperated and enjoy the same quality of life they did before they got hurt. | Research suggests that risky outdoor play is good for children's health and encourages creativity, social skills and resilience. Parents and caregivers should encourage physical activity while being aware of the possibility of injury and take steps to prevent unnecessary risks. | System: Knowledge dissemination               |
| Researchers with the BC Injury Research and Prevention Unit at BC Children's Hospital led knowledge translation efforts to promote risky play within the Corporation of Delta. These efforts resulted in a policy change, increased funding for playgrounds that introduce risk through natural play elements, and the opening of two new adventure playgrounds in summer 2017.  | Research suggests that risky outdoor play is good for children's health and encourages creativity, social skills and resilience. Risky play promotes active lifestyles and gives children a chance to learn about risk and their own limits.   | System: Knowledge<br>dissemination-new policy |
| The Council of Chief Medical Officers of Health (CCMOH) has developed a position paper to endorse the Position Statement on Active Outdoor Play. A researcher with the BC Injury Prevention Unit (BCIRPU) at BC Children's Hospital contributed to the development of this position paper through a presentation to the CCMOH. This presentation was later used by Dr. Gregory Taylor, Canada's then Chief Public Health Officer, in his plenary address at the 2016 Canadian Public Health Association Conference. The Position Statement on Active Outdoor Play was developed by a consortium of organizations including the BCIRPU, and was also informed by BCIRPU research.                                       | Research suggests that risky outdoor play is good for children's health and encourages creativity, social skills, and resilience. Risky play promotes active lifestyles and gives children a chance to learn about risk and their own limits.  | System: Knowledge dissemination               |



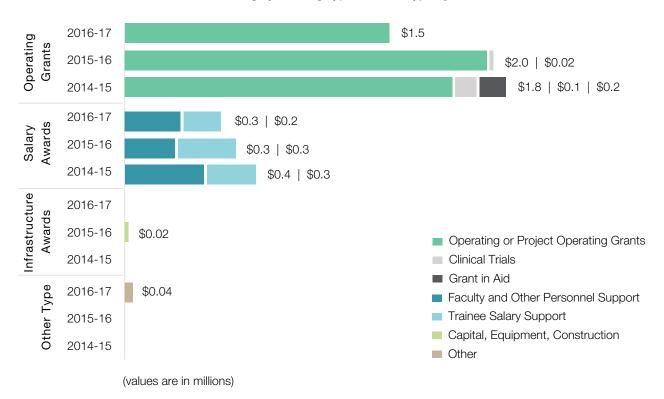
An agency of the Provincial Health Services Authority

#### **Producing and Advancing Knowledge**

In FY 2016-17, researchers associated with BCMHSUS, were awarded a total of \$2,020,660. Operating grants and Salary awards make up the majority (98.5%) of awards. A breakdown of funding types and subtypes can be found in Figure 36. The drop in award funding from FY 15-16 to FY 16-17 is primarily driven by a drop in grants awarded to PHSA Mental Health Research Program researchers from the non-profit sector, specifically BCCHR one-time funding

awards that were made available in the 2015–16 fiscal year. Tri-council funded research was also down following the end of some large multi-year operating grants. Industry and government funding increased slightly in the same time period. BCMHSUS's portion of the Indirect Costs Program grant totaled \$185,398 for FY 2016–17 but is not included in total research funding or the figures below.

FIGURE 36 BCMHSUS Research Funding by Funding Type and Sub-type by Fiscal Year



the largest. Figure 38 details the major funding categories by RISe sector, funding source category and funding type.

FIGURE 37 Percentage of BCMHSUS Research Funding by Funding Source Category by Fiscal Year

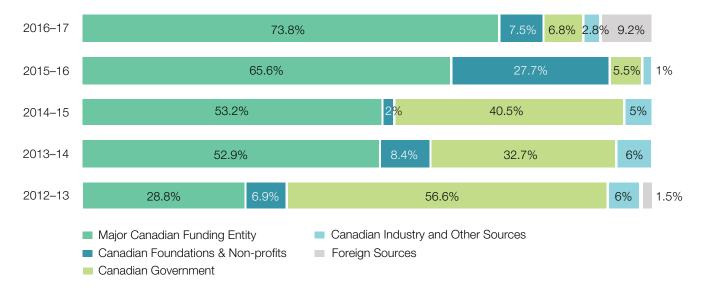
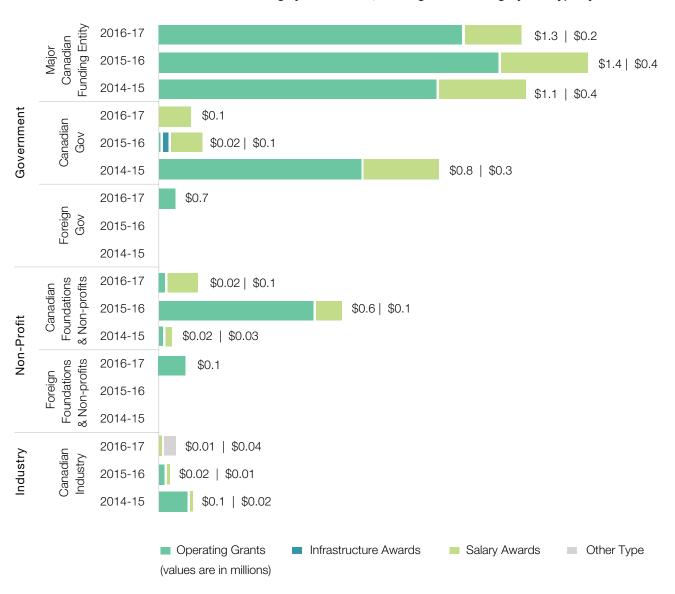


FIGURE 38 Total BCMHSUS Research Funding by RISe Sector, Funding Source Category and Type by Fiscal Year

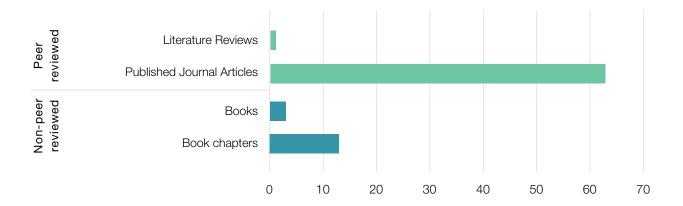


BCMHSUS had two (2) Foundation Scheme Open Competition and four (4) Project Grant Applications in 2016 resulting in one (1) approved Project grant.

BCMHSUS had a total of 80 publications of which 80% were peer reviewed. Total number of publications by type

and category (peer vs. non-peer reviewed) is seen in Figure 39. The agency total represents the number of publications where at least one agency researcher was an author of the publication. When researchers from more than one research entity/agency collaborate on the same publication, it is counted once for each agency.

FIGURE 39 Total Number of BMHSUS Publications by Type and Category



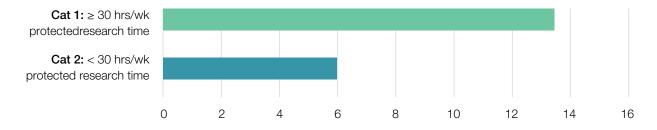
#### **Building Research Capacity**

BCMHSUS had a total of 19.5 researchers in FY 2016–17, with 13.5 having greater than 30 hours of protected research time per week (Figure 40). While this is a decrease from previous years, a number of BCMHSUS clinicians engaged in research are now counted in the BCCHR totals following the

operational transfer of Child & Youth Mental Health back to BC Children's Hospital.

During FY 2016–17, BCMHSUS researchers provided training and supervision to a total of 95 trainees (see Figure 41).

FIGURE 40 Total Number of BCMHSUS Researchers by Category



30 25 20 15 10 5 0 Post-doctoral Summer student Other Masters Doctoral Practicum Resident Fellows Co-op, honours, (short term) & directed studies

students

FIGURE 41 Total Number of BCMHSUS Trainees by Category

# **Advancing Health and Policy Benefits**

See Table 12 for a detailed breakdown of clinical trial activity by fiscal year. Of note is that all of BCMHSUS trials

2015-16

2014-15

contained enrollment figures in all REB (Research Ethics Board) records.

**TABLE 12 BCMHSUS Clinical Trials** 

2016-17

|  | 11–12 | 12–13 | 13–14 | 14–15 | 15–16 | 16–17 |
|--|-------|-------|-------|-------|-------|-------|
| Total Number of Clinical Trials active during the FY         | 9     | 10    | 7     | 5     | 4     | 2     |
| Status of the Trial at the end of the FY:                    |       |       |       |       |       |       |
| Total Number of Active Trials                                | 9     | 10    | 7     | 5     | 4     | 2     |
| Total Number of Trials that closed during the FY             | 6     | 5     | 2     | 0     | 0     | 0     |
| Enrolment Numbers:   |       |       |       |       |       |       |
| Expected Local Subject Enrolment (for the term of the study) | 618   | 828   | 688   | 563   | 640   | 450   |
| Total Cumulative Subject enrolment at the end of the FY      | 323   | 16    | 56    | 77    | 228   | 244   |

For the first time, grant funding type is reported for Clinical Trials. This information is sourced from the REB (Research Ethics Board) file and reflects the funding type entered as part of the ethics application (see glossary, page 85 for a definition of funding types). 100% of BCMHSUS' clinical trials are grant funded.

BC Mental Health and Substance Use Research Program had no key guidelines, drugs, diagnostic agents or devices adopted or approved in FY 2016–17 as a result of research driven by BCMHSUS researchers, and their corresponding benefits.



# **BC Centre for Disease Control**

An agency of the Provincial Health Services Authority

#### **Producing and Advancing Knowledge**

In FY 2016–17, researchers affiliated with BCCDC/UBC CDC were awarded a total of \$3,239,582 in research funding. The amount awarded as Operating Grants (\$2,699,293) makes up 83% of total awards. A breakdown of funding types and subtypes can be found in Figure 42 and by funding source category in Figure 43. BCCDC's portion of the

Indirect Costs Program grant totaled \$93,936 for FY 2016–17 but is not included in total research funding or the figures below. Because of its public and population health mandate, research at BCCDC is very much embedded within its clinical mandate and, as such, is also supported by operating funding to a significant degree.

FIGURE 42 Total BCCDC/UBC CDC Research Funding by Funding Type and Sub-type by Fiscal Year

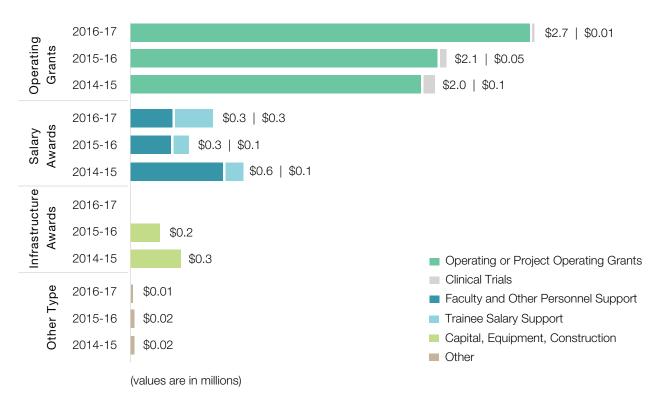
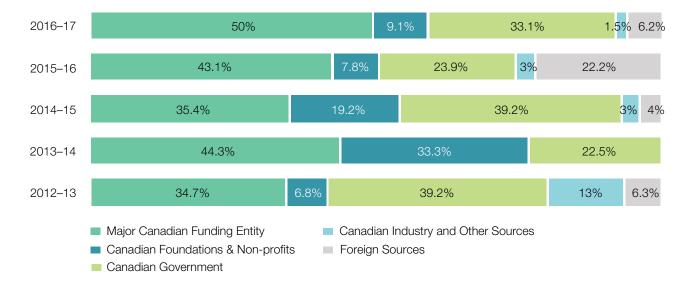
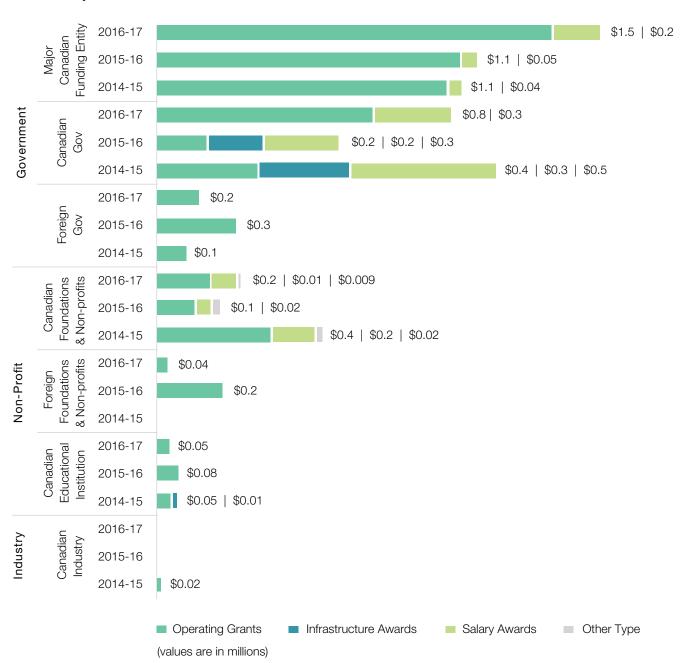


FIGURE 43 Percentage of BCCDC/UBC CDC Research Funding by Funding Source Category by Fiscal Year



details the RISe sector and major funding categories by funding type.

FIGURE 44 Total BCCDC/UBC CDC Research Funding by RISe Sector, Funding Source Category and Type by Fiscal Year

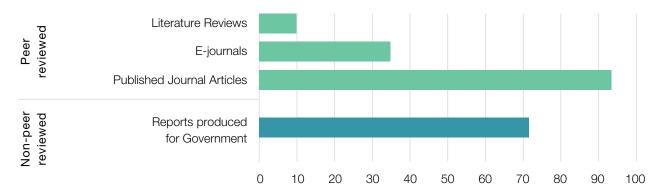


BCCDC has a total of 2 approved applications from the CIHR Sept 2016 Project Grant competitions.

BCCDC had a total of 211 publications of which 67% were peer reviewed. Total number of publications by type and category (peer vs. non-peer reviewed) is seen in Figure

45. The agency total represents the number of publications where at least one agency researcher was an author of the publication. When researchers from more than one research entity/agency collaborate on the same publication, it is counted once for each agency.

FIGURE 45 Total Number of BCCDC/UBC Publications by Type and Category

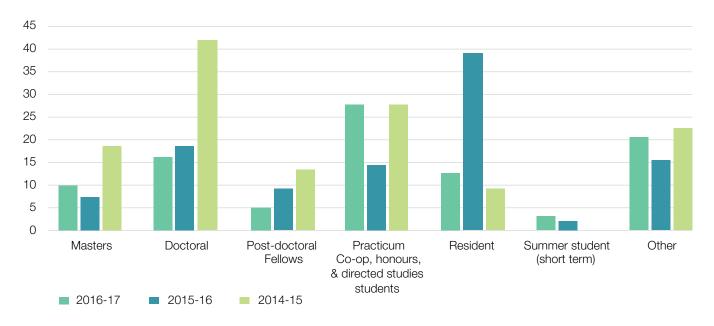


#### **Building Research Capacity**

BCCDC/UBC CDC defines a researcher as any principal investigator or co-investigator involved in BCCDC/UBC CDC research projects. BCCDC had a total of 34.5 researchers meeting this definition in FY 2016-17.

During FY 2016–17, BCCDC/UBC CDC researchers provided training and supervision to a total of 95 trainees (see Figure 46).

FIGURE 46 Total Number of BCCDC/UBC CDC Trainees by Type



#### Advancing Health and Policy Benefits

Clinical trial data from the REB is provided for a third year utilizing the same methodology as last year. See Table 13 for a detailed breakdown of clinical trial activity by fiscal year.

TABLE 13 BCCDC/UBC CDC Clinical Trials

|  | 11–12 | 12–13 | 13–14 | 14–15 | 15–16 | 16–17 |
|--|-------|-------|-------|-------|-------|-------|
| Total Number of Clinical Trials active during the FY         | 2     | 2     | 2     | 3     | 4     | 5     |
| Status of the Trial at the end of the FY:                    |       |       |       |       |       |       |
| Total Number of Active Trials                                | 2     | 2     | 2     | 3     | 4     | 5     |
| Total Number of Trials that closed during the FY             | 0     | 0     | 0     | 0     | 0     | 0     |
| Enrolment Numbers:   |       |       |       |       |       |       |
| Expected Local Subject Enrolment (for the term of the study) | 532   | 532   | 532   | 401   | 2,000 | 2,696 |
| Total Cumulative Subject enrolment at the end of the FY      | 203   | 325   | 55    | 157   | 294   | 2,656 |

For the first time, grant funding type is reported for Clinical Trials. This information is sourced from the REB (Research Ethics Board) file and reflects the funding type entered as part of the ethics application (see glossary, page 85 for a definition of funding types). Eighty percent (80%) of BCCDC's clinical trials are grant funded with the remaining 20% with no funding.

Table 14 reflects a sample of key guidelines, drugs, diagnostic agents or devices adopted or approved in FY 2016-17 as a result of research driven by BCCDC/UBC CDC researchers, and their corresponding benefits. These outcomes represent important achievements in translational research that are improving patient outcomes and system sustainability.

TABLE 14 BCCDC/UBC CDC Outcomes Survey Responses

| Please describe any guideline, drug, diagnostic agent or device adopted or approved in 2016/17 as a result of research driven by PHSA researchers.   | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.   | Type of Benefit                   |
|--|---|-----------------------------------|
| Our work in developing a genomic epidemiology approach to outbreak reconstruction was cited in the new American Thoracic Society/Infectious Diseases Society of America/Centers for Disease Control and Prevention Clinical Practice Guidelines: Diagnosis of Tuberculosis in Adults and Children. The genome-based approach to identifying clusters of related TB cases was noted as an effective tool for enhancing strain discrimination. | Identifying and controlling TB outbreaks requires finding genetically linked cases and uncovering the epidemiological relationships driving disease transmission. The genomic approach we pioneered provides the highest level of resolution possible when identifying related cases. | Patient: Protocols and guidelines |
| Significant updates to the Bugs and Drugs Antibiotic Prescribing Guidelines. The guidelines are also now fully web accessible for free to BC Prescribers.  | Part of a program that has reduced unnecessary prescribing, dropped overall prescribing by 15% and saved over 50 M per year in costs.   | Patient: Protocols and guidelines |
| BCCDC research contributed to the Online Dental Continuing Education Tool to reinforce antibiotic prescribing guidelines.  | Dentists have accounted or an increasing proportion of prescriptions. This is part of the effort to reverse the trend.  | Patient: Protocols and guidelines |

| Please describe any guideline, drug, diagnostic agent or device adopted or approved in 2016/17 as a result of research driven by PHSA researchers.   | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.  | Type of Benefit                   |
|--|--|-----------------------------------|
| At a time when there was a vacuum of guidance on Zika surveillance, advice and response, BCCDC researchers conducted epidemiological research which led to the formulation of the Zika virus diagnosis, surveillance and follow-up guidelines which resulted in a change in practice.  | These guidelines allowed BC to respond in a nimble fashion to a new epidemic.  | Patient: Protocols and guidelines |
| BCCDC research evidence informed the World Health<br>Organization Drug Sensitive Tuberculosis Treatment<br>Guidelines  | Improved treatment for TB globally   | Patient: Protocols and guidelines |
| BCCDC research led to the development of the BC Asthma Prediction System (BCAPS). Each BCAPS report provides information about (1) observed and predicted air quality and (2) observed and predicted dispensations of salbutamol sulphate.   | Reports from BCAPS are intended for use by BC public health professionals to support health protection during forest fire smoke events. They provide Medical Health Officers and other stakeholders with estimates of how smoke can be expected to affect the population over the next 24 hour (today) and 24 hours (tomorrow).  | System: Other type                |
| Evaluation of ongoing monitoring of coarse particular matter (PM10) in addition to fine particulate matter (PM2.5) across BC. BC Ministry of Environment (MOE) asked BCCDC Environmental Health Services for research evidence to evaluate dust monitors and help decide whether the coarse fraction instruments should be retired or replaced. Based on the evidence provided by BCCDC researchers, the BC MOE replaced the dust monitors instead of retiring them.   | We looked at the relationship between ambient concentrations of the coarse fraction and daily mortality among interior communities regularly affected by road dust. During the spring road dust season a 10-ug/m3 increase in the coarse fraction was associated with a 3.6% [1,6.2] increase in all-cause mortality. As a direct result the BC MOE has decided to replace the dust monitors, rationalizing the network to prioritize communities affected by road dust. | System: Other type                |
| Peer Engagement Principles and Best Practices: A guide for BC Health Authorities and other providers  Peer engagement is the active participation of people with lived experience of substance use in research, program, and policy decision-making processes. Peers can provide insights into the realities of substance use and their local risk environments, and the applicability of programs and policies. Peer engagement can be mutually beneficial in promoting health equity in programs and policies while building capacity for peers and Health Authority representatives. The principles outlined in this report provide justification and support for enhancing peer engagement among BC Health Authorities and include the definition and importance of peer engagement, consideration of power dynamics, benefits to peer and providers, regional differences, stigma and trust, organizational support, and independent networks of peers. Peer engagement practices are not limited to one-on-one participation processes; they include certain considerations in the preparation, engagement, support, and conclusion stages of peer engagement. This document provides both an overview and details of these processes to support meaningful and equitable engagement between Health Authority representatives and peers. | Promoting peer engagement within Health Authorities can improve the involvement and uptake of peers' voices in health service planning and policy making in BC. Individuals who work in Health Authorities can use these peer engagement principles and best practice guidelines to foster meaningful engagement, which can in turn promote positive relationship and capacity building for everyone involved.   | Patient: Protocols and guidelines |

| Please describe any guideline, drug, diagnostic agent or device adopted or approved in 2016/17 as a result of research driven by PHSA researchers.  | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.  | Type of Benefit  |
|---|--|--|
| A Guide for Paying Peer Research Assistants: Challenges and Opportunities  Community based participatory research (CBPR) has been described as a collaborative approach to research that involves community partners in the research process, and integrates education and social action to improve health and reduce health disparities while involving community partners in the research process, and insuring that action is a part of the research process itself. Best practice in CBPR is compensating peer research assistants (PRAs) for the work that they do rather than expecting them to volunteer their time. This guide summarizes some of the complex but accessible online policies, although these are frequently and regularly updated. The information gained through this paper will help address existing bureaucratic inefficiencies and may be used to streamline future CBPR partnerships. | A key feature of CBPR is that it can provide employment opportunities for members of the community. Collaborative and equitable partnerships with peers can improve the effectiveness, relevance, and acceptability of projects by ensuring the questions, approaches, and mediums for dissemination are appropriate. For peers, employment in CBPR can improve self-esteem by validating knowledge and experience, and can boost morale, decrease isolation, and increase capacity. For organizations, involving peers can change perceptions of an often marginalized and stigmatized group. | Patient: Protocols and guidelines  |
| WHO vaccine strain selection for the northern & southern hemispheres  Recommendations for reformulation of influenza vaccine components for the southern hemisphere's 2017 influenza season (determined in September 2016) and the northern hemisphere's 2017–18 season (determined in February 2017), was informed in part by BCCDC-led research. The recommendations were based on research findings related to genetic, antigenic and epidemiologic monitoring of influenza vaccine-virus relatedness and effectiveness provided by the Canadian Sentinel Practitioner Surveillance Network (SPSN) to the WHO Vaccine Strain Selection Committee through the Global Influenza Vaccine Effectiveness (GIVE) consortium and published in numerous international journals including EuroSurveillance, and Journal of Infectious Disease.  | Vaccine strain selection by the WHO helps determine the protection provided by vaccination to tens of millions of individuals globally.  | Patient: delay of disease progression/survival; Patient: access to new treatment/technology; System: Knowledge dissemination-new policy; System: resource improvements-workforce |
| WHO's Evaluation of Influenza Vaccine Effectiveness: A Guide to the Design and Interpretation of Observational Studies  A BCCDC researcher was one of a handful of expert advisors consulted for the WHO's just-released Evaluation of Influenza Vaccine Effectiveness: A guide to the design and interpretation of observational studies. The Canadian Influenza Sentinel Practitioner Surveillance Network (SPSN) figures prominently in these guidelines.  | Research and analyses ensure health care resources are used wisely, and identify aspects needing improvement. This WHO guide helps countries apply sound methodology in the evaluation of influenza vaccine performance so that influenza vaccine effectiveness findings will be as reliable as possible.  | System: Knowledge dissemination-new policy   |

| Please describe any guideline, drug, diagnostic agent or device adopted or approved in 2016/17 as a result of research driven by PHSA researchers.  | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.   | Type of Benefit   |
|---|---|---|
| Contribution to influenza vaccine policy in Canada and abroad – WHO Expert Input, NACI and US CDC annual statements on seasonal influenza vaccine use  Research findings of the BCCDC Influenza Team were presented to the World Health Organization (WHO), various provincial communicable disease policy committees (e.g. BC and Quebec) to inform immunization control manuals, and to Canada's National Advisory Committee on Immunization to inform guidelines on the use of seasonal influenza vaccine for 2016–17 and 2017-18, including recent evidence related to evaluation of LAIV (live attenuated influenza vaccine) and inactivated influenza vaccine and the effects of annually repeated influenza vaccination. Findings of the BCCDC Influenza Team were also cited by Advisory Committee on Immunization Practices recommendations for influenza vaccine use. | Ensuring public health policies and programs are informed by the best scientific evidence on influenza vaccine protection.  | Patient: delay of disease progression/survival; Patient: protocols and guidelines; Patient: access to new treatment/technology; System: Knowledge dissemination-new policy; System: resource improvements-workforce |
| Influenza TND methodology recognized by Accreditation Canada as a Leading Practice.  Leadership in influenza VE assessment methodology: the TND (test-negative design) was developed by a researcher at the BC Centre for Disease Control and has been adopted by multiple countries globally as an efficient way to monitor annual influenza vaccine effectiveness. The methodology was recognised by Accreditation Canada as a Leading Practice.  | Influenza vaccination programs represent an enormous investment of health care resources. Research and analyses ensure those resources are used wisely. Millions of Canadians and people around the world rely on the influenza vaccine to protect them from influenza infection. The annual assessment of vaccine effectiveness is a key check on those programs and critical knowledge for optimizing our influenza immunization program. | System: process of care-<br>standardization; System:<br>process of care-protocol<br>implementation  |

# WOMEN'S HEALTH RESEARCH INSTITUTE AT BC WOMEN'S

#### **Producing and Advancing Knowledge**

In FY 2016–17, researchers affiliated with WHRI were awarded a total of \$2,576,221 in research funding, which represents a 19% decrease over last year. The amount awarded as Operating Grants (\$2,030,928) makes up 79% of total awards and is a 48% increase over last FY. A breakdown of funding types and subtypes can be found in Figure 47 and by funding source category in Figure 48. WHRI's portion of the Indirect Costs Program grant totaled \$149,653

for FY 2016–17 but is not included in total research funding or the figures below. WHRI shares investigators with a number of other health research institutes and universities and benefits from additional external grant revenues linked to these investigators. At this time, those research dollars are only included if a formal transfer agreement is in place to allocate attribution of shared investigator grants. As a result, total research funding below is understated.

FIGURE 47 Total WHRI Research Funding by Funding Type and Sub-type by Fiscal Year

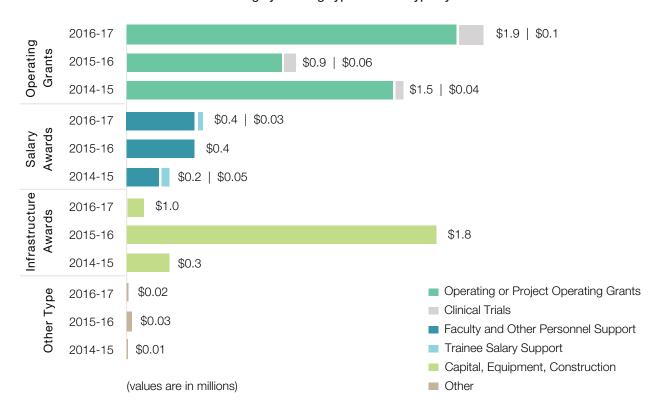


FIGURE 48 Percentage of WHRI Research Funding by Funding Source Category by FY

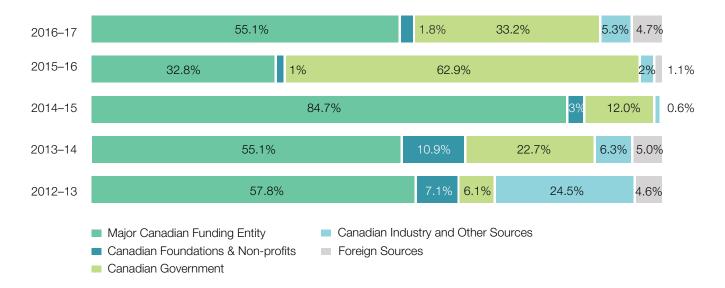
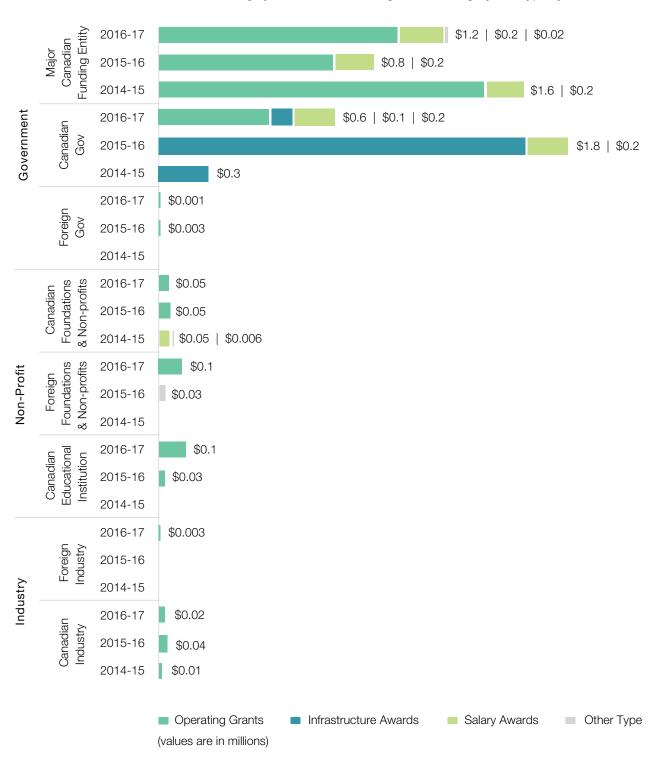


FIGURE 49 Total WHRI Research Funding by RISe Sector, Funding Source Category and Type by Fiscal Year

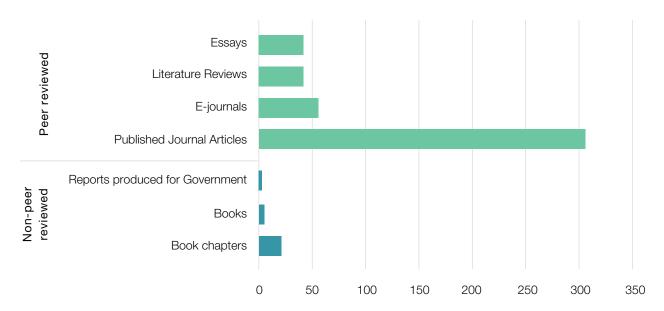


WHRI had three (3) grants approved in the CIHR October 2016 Project Grant competition. WHRI investigators apply for grant competitions that are offered by a variety of granting agencies.

WHRI had a total of 476 publications in calendar year 2016 of which 94% were peer reviewed. Total number of publications

by type and category (peer vs. non-peer reviewed) is shown in Figure 50. Peer review represents the gold standard for scientific credibility. The agency total represents the number of publications where at least one agency researcher was an author of the publication. When researchers from more than one research entity/agency collaborate on the same publication, it is counted once for each agency.

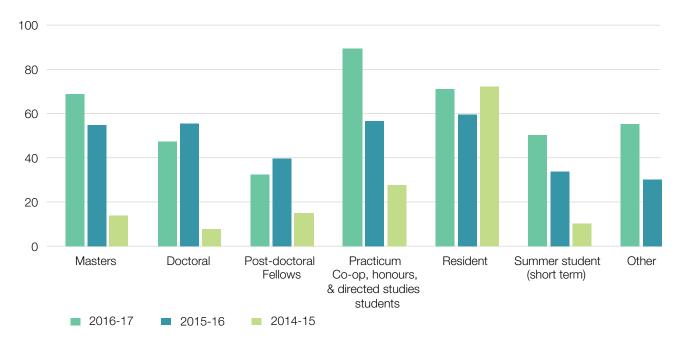
FIGURE 50 Total Number of WHRI Publications by Type and Category



# **Building Research Capacity**

WHRI researchers provided training and supervision to a total of 402 trainees, a large increase over FY 2015-16 (see Figure 51). This increase is attributed to more accurate reporting of actual trainees plus the addition of new members who actively supervise trainees.

FIGURE 51 Total Number of WHRI Trainees by Type

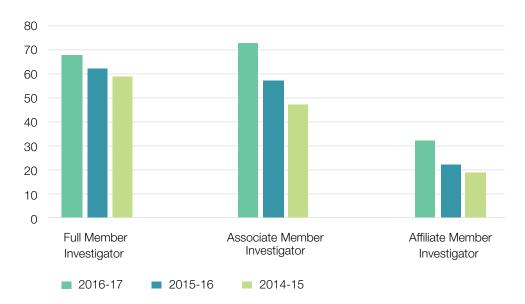


In an effort to show WHRI's activities, their membership statistics are shown (see Figure 52). In FY 2016-17,

membership increased by 32 for a total of 173 members. The membership categories are as follows:

| Full Member      | Individuals involved in women's health research for which the WHRI would be the only research institute affiliation.  |
|------------------|---|
| Associate Member | Individuals who are involved in women's health research, at least in part, but have a strong relationship with another research institute (e.g. BCCHR) that they wish to maintain; the result is a dual membership with the WHRI and their current affiliation. |
| Affiliate Member | Individuals who are extensively involved with another institute, but may have projects that would overlap with WHRI.  |

FIGURE 52 Total WHRI Membership by Category



# **Advancing Health and Policy Benefits**

Clinical trial data from the REB (Research Ethics Board) is provided for a fourth year utilizing the same methodology as last year. See Table 15 for a detailed breakdown of clinical trial activity by fiscal year. Of note is that approximately 27% of WHRI trials had no enrollment figures, down 5% from last FY.

**TABLE 15 WHRI Clinical Trials** 

|  | 11–12 | 12–13 | 13–14 | 14–15 | 15–16 | 16–17 |
|--|-------|-------|-------|-------|-------|-------|
| Total Number of Clinical Trials active during the FY         | 30    | 26    | 26    | 27    | 28    | 11    |
| Status of the Trial at the end of the FY:                    |       |       |       |       |       |       |
| Total Number of Active Trials                                | 30    | 26    | 26    | 20    | 24    | 7     |
| Total Number of Trials that closed during the FY             | 13    | 7     | 6     | 7     | 4     | 4     |
| Enrolment Numbers:   |       |       |       |       |       |       |
| Expected Local Subject Enrolment (for the term of the study) | 4,479 | 3,694 | 3,709 | 3,433 | 4,058 | 1,162 |
| Total Cumulative Subject enrolment at the end of the FY      | 1,885 | 2,223 | 1,811 | 1,940 | 2,360 | 545   |

For the first time, grant funding type is reported for Clinical Trials. This information is sourced from the REB (Research Ethics Board) file and reflects the funding type entered as part of the ethics application (see glossary, page 85 for a

definition of funding types). Thirty-seven percent (37%) of WHRI's clinical trials are Grant funded, and 27% are Industry funded. See Figure 53 for a breakout of trials by funding type.

FIGURE 53 WHRI's Percentage of Clinical Trial Grant Funding Type: Active and Terminated Trials within the FY

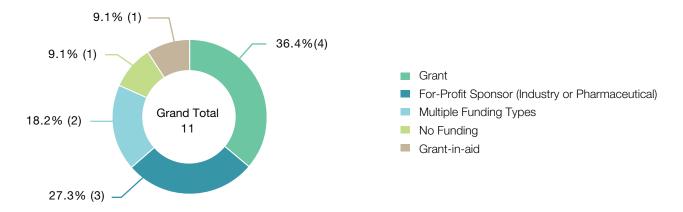


Table 16 reflects a sample of key guidelines, drugs, diagnostic agents, or devices adopted or approved in FY 2016-17 as a result of research driven by WHRI researchers, and their corresponding benefits. These outcomes represent important achievements in translational research that are improving patient outcomes and system sustainability.

**TABLE 16 WHRI Outcomes Survey Responses** 

| Please describe any guideline, drug,<br>diagnostic agent or device adopted or<br>approved in 2016/17 as a result of research<br>driven by PHSA researchers.   | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.  | Type of Benefit   |  |  |  |  |
|---|--|---|--|--|--|--|
| Research findings and recommendations from a WHRI researcher resulted in a national policy change by Health Canada regarding the regulation of the newly approved drug, Mifepristone, used for the medical termination of pregnancy. This research and advocacy also resulted in two provincial policy changes in British Columbia regarding the regulation and dispensing of Mifepristone. | Improved outcomes for women due to increased access to treatment for the medical termination of pregnancy. Cost savings to women in British Columbia, who will now have access to free mifepristone at all hospitals, greatly improving rural and remote access to this abortion drug which otherwise may cost women up to \$400 dollars per dose.   | Patient: Access to new treatment or technology System: Efficiency, cost/benefit or sustainability; Knowledge disseminationnew policy  |  |  |  |  |
| WHRI researcher was the principal author of a national guidance document: <i>Hepatitis B and Pregnancy</i> .  | This guidance document will provide guidance to obstetric care providers when counseling pregnant women with hepatitis B virus (HBV) regarding perinatal risks and management options. Increased maternal and perinatal safety and cost savings due to standardization of HBV anti-viral treatment for the prevention of perinatal transmission and invasive procedures during pregnancy for women with HBV infection. | Patient: Delay of disease progression/survival System: Knowledge dissemination-new policy; Efficiency, cost/benefit or sustainability |  |  |  |  |

| Please describe any guideline, drug,<br>diagnostic agent or device adopted or<br>approved in 2016/17 as a result of research<br>driven by PHSA researchers.   | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.   | Type of Benefit  |
|---|---|--|
| WHRI researcher was the principal investigator of a study on childbirth in BC that led to the development of new scales which measure women's experience of communication with maternity care providers. These tools have been included in a World Health Organization global scan for novel instruments to assess quality and safety across high and low resource countries. | Improved maternal wellbeing due to the promotion of respect and autonomy for women's decision making in communication exchange with maternity care providers. Improved maternal and fetal health by assuring benchmark levels of maternity care quality and safety internationally. | Patient: Access to new treatment or technology System: Knowledge dissemination-new policy  |
| Based on research evidence provided by a WHRI researcher, the International Consultation on Sexual Medicine guidelines on sexual dysfunction have been revised to include mindfulness-based therapy as a recommended treatment for low sexual desire in women.  | Improved outcomes for women suffering from low sexual desire due to the availability of a novel, evidence-based therapy. Cost savings due to care being delivered via a group treatment model versus a standard one-on-one therapy setting.   | Patient: Access to new<br>treatment or technology<br>System: Efficiency, cost/<br>benefit or sustainability;<br>Knowledge dissemination-<br>new policy |
| WHRI researcher was the principal author of the national clinical practice guideline: <i>Amniotic Fluid: Technical Update on Physiology and Measurement.</i>  | Improved maternal and perinatal outcomes due to reduced interventions as a result of the diagnosis of oligohydramnios without increasing adverse outcomes. Cost savings by promoting the more efficient use of ultrasound assessment.   | Patient: Protocols and guidelines System: Knowledge dissemination-new policy; Efficiency, cost/benefit or sustainability                               |
| WHRI researcher was one of the co-authors of a national clinical practice guideline: Canadian Contraception Consensus Part 4 of 4 Chapter 9: Combined Hormonal Contraception.   | Provides guidance to Canadian health care providers on the use of contraceptive methods to prevent pregnancy and on the promotion of healthy sexuality.  Cost savings and increased patient safety by recommending the use of effective, low-risk methods of contraception.         | Patient: Protocols and guidelines System: Efficiency, cost/benefit or sustainability; Knowledge disseminationnew policy                                |
| Based on evidence from a WHRI researcher, specific components within the endometrial cancer classification system used at the BC Cancer Agency and other centers have been updated.   | Improved outcomes for women suffering from endometrial cancer due to more accurate classification of cancer subtypes, which will result in better targeted treatment.   | Patient: Protocols and guidelines System: Knowledge dissemination-new policy; Process of care-standardization  |
| WHRI researcher participated in the Diagnostic Imaging Committee that led to the development of the national clinical practice guideline: Ultrasound Evaluation of First Trimester Complications of Pregnancy.  | Improved maternal and perinatal outcomes due to increased accuracy and improved safety in the diagnosis of early pregnancy loss and ectopic pregnancy.  Reduced maternal morbidity and mortality due to earlier diagnosis and clinical management of ectopic pregnancy.             | Patient: Protocols and guidelines System: Knowledge dissemination-new policy; Process of care-standardization  |
| Research evidence provided by a WHRI/BCCHRI researcher was used by the World Health Organization to inform their guidance document: Evaluation of influenza vaccine effectiveness: a guide to the design and interpretation of observational studies.   | Improved public health world-wide due to the use of effective, evidence-based influenza vaccination policies. Improved public safety due to reduced disease transmission in the event of a local influenza outbreak.  | Patient: Delay of disease progression/survival System: Knowledge dissemination-new policy; Process of care-standardization                             |

| Please describe any guideline, drug,<br>diagnostic agent or device adopted or<br>approved in 2016/17 as a result of research<br>driven by PHSA researchers.  | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.  | Type of Benefit  |
|--|--|--|
| Based on research and advocacy by a WHRI researcher, the B.C. Government implemented a policy to provide free contraception methods for all women and girls in the province at the time of abortion.   | Improved outcomes for women with at the time of abortion due to the availability of free, highly effective methods of contraception. Cost savings due to reduced need for medical care due to future unintended pregnancies.   | Patient: Delay of disease<br>progression/survival<br>System: Knowledge<br>dissemination-new policy;<br>Efficiency, cost/benefit or<br>sustainability |
| WHRI researcher participated in the Diagnostic Imaging Committee that led to the development of the national clinical practice statement: Joint CAR/SOGC Statement on Performing Ultrasound Examinations of the Female Pelvis  | This joint statement was developed in accordance with existing international standards to provide guidance to health care practitioners performing ultrasound examinations of the female pelvis. Improved health for women due to the standardization of practice resulting in optimized radiological care.  | Patient: Protocols and guidelines System: Knowledge dissemination-new policy; Process of care-standardization  |
| WHRI researcher was a special contributor to the development of a national guidance document: Management of Spontaneous Labour at Term in Healthy Women  | Improved maternal and perinatal outcomes due to evidence-based recommendations for the management of spontaneous intrapartum labour in term, healthy women. Cost savings due to the increased likelihood of a vaginal birth and optimized birth outcomes, thus, minimizing the costs of birth complications.   | Patient: Protocols and guidelines System: Knowledge dissemination-new policy; Efficiency, cost/benefit or sustainability                             |
| Based directly on research evidence provided by a WHRI researcher, Prison Health Program Committee created the national guidance document: College of Family Physicians of Canada's Position Statement on Health Care Delivery.  | Recommends that the responsibility for the delivery of health care in Canadian correctional facilities be transferred from judicial to health ministries at all levels.  If adopted, this will optimize the provision of health services such that individual and public health issues are addressed according to national and provincial/territorial standards of best practices.     | Patient: Protocols and guidelines System: Knowledge dissemination-new policy; Process of care-standardization  |
| WHRI researcher was one of the authors of the national clinical practice guideline: Hypertension Canada's 2017 Guidelines for Diagnosis, Risk Assessment, Prevention, and Treatment of Hypertension in Adults  | This updated guideline will lead to improved blood pressure screening due to evidence-based recommendations to guide the diagnosis, assessment, prevention, and treatment of hypertension.   | Patient: Delay of disease progression/survival; Protocols and guidelines System: Knowledge dissemination-new policy                                  |
| A WHRI/BCCHRI researcher is leading a study on Canada's first prenatal education program delivered via text-messaging. This program has already been launched in the Northern Health Authority and it will be expanded into the Fraser, Interior and Island Health Authorities shortly.  | Improved maternal and perinatal health through the provision of evidence-based prenatal education to groups of pregnant women in British Columbia who might otherwise receive this type of education (i.e., because of lack of local resources or an inability to access existing programs). Cost savings due to the virtual administration (via smartphone) of the education program. | System: Knowledge<br>dissemination-new<br>policy; Process of care-<br>standardization; Efficiency,<br>cost/benefit or sustainability                 |
| WHRI researcher participated in an International consortium that developed standard operating procedures for assessing blood pressure in research subjects:  Recommended Standards for Assessing Blood Pressure in Human Research Where Blood Pressure or Hypertension is a Major Focus. | Improved world-wide collection of population health-level data on blood pressure and hypertension through the standardized acquisition of blood pressure measurement in research participants, which will allow for more accurate and large-scale collaborative research into these conditions.  | System: Knowledge<br>dissemination – new policy  |

| Please describe any guideline, drug,<br>diagnostic agent or device adopted or<br>approved in 2016/17 as a result of research<br>driven by PHSA researchers.   | Please describe the benefits to patients, population health, and/or health system sustainability of the items identified.   | Type of Benefit   |
|---|---|---|
| Based on research evidence and recommendations made by a WHRI researcher, a process of shared decision-making regarding mode of delivery (via a patient decision aid) was incorporated into a quality standard policy in Ontario: Health Quality Ontario's Vaginal Birth After Caesarean (VBAC). Also, based on this research evidence, Perinatal Services BC added a new provincial indicator for attempted VBAC to their list of surveillance data. | Improved maternal wellbeing due to the promotion of respect and autonomy for women's decision making in communication exchange with maternity care providers. Improved provincial maternal health surveillance due to the better optimized collection of health outcome data.           | Patient: Protocols and guidelines System: Knowledge dissemination-new policy                                  |
| Based on research evidence provided by a WHRI researcher, the Prison Health Community of Practice in Family Medicine created the national guidance document: College of Family Physicians of Canada's Position Statement on Solitary Confinement.   | Recommends that the use of solitary confinement be abolished in Canadian correctional facilities due to the negative physical and psychological consequences on prisoners' well-being. If adopted, this will result in improved health outcomes for incarcerated populations in Canada. | Patient: Protocols and guidelines System: Knowledge dissemination-new policy; Process of care-standardization |

# REGISTRIES & DATASETS

#### Advancing Health and Policy Benefits

For a fourth year, data was collected from PHSA's registries and data sets to capture information to allow identification of users of the databases, how the data support research and a benefit classification which provides a deeper understanding of the benefits resulting from the use of these data for research.

Data stewards for a total of 18 PHSA registries or datasets, were invited to participate in a survey designed to assess the research activities of the registry/dataset. Completed surveys from 15 out of the 18 registries/datasets were obtained. The Research Metrics working group drew a distinction between two types of databases that might be counted. The first are those that serve as registries. These are the result of

significant infrastructure investment in the collection of longitudinal data that are regional, provincial or national in scope regarding provision of services to specific population(s), maintained for the purposes of undertaking analysis, surveillance and/or research. They represent a significant resource for and investment in research. The second (not collected) are short-term, project-related databases that are primarily grant funded and are not maintained for use beyond the term of a given research project.

# Registry/Data set Definition/Purpose

The information on each registry/dataset was compiled from online resources and is described below.

| Registry/Dataset                       | Purpose   |
|--|---|
| BC Cancer Registry                     | The BC Cancer Registry is a population-based registry of all cancers diagnosed in British Columbia residents. It collects data and generates cancer statistics on the BC Population for the purpose of monitoring the burden of cancer in the province. It also serves as a source of information for research.   |
| BC Cardiac Registry (HEARTis)          | Heart Information System (HEARTis) tracks a patient journey for all current and future cardiac procedures, throughout British Columbia, from registry on the waitlist to procedure completion and follow up. Its purpose is to support clinical care, quality assurance and improvement, and outcome-based research.  |
| BC Generations Project                 | The BC Generations Project is British Columbia's largest-ever health study. The Project follows a cohort of nearly 30,000 BC participants who volunteer their health information and biological samples to help researchers learn more about how environment, lifestyle and genes contribute to cancer and other chronic diseases.  |
| BC Perinatal Database Registry (BCPDR) | The (BCPDR) contains data abstracted from obstetrical and neonatal medical records on nearly 100% of births in the province of British Columbia from over 60 hospitals as well as births occurring at home attended by BC registered midwives. The BCPDR also collects data on maternal postpartum readmissions up to 42 days post-delivery and baby transfers and readmissions up to 28 days after birth. Data access is provided for public-interest research purposes, surveillance, program delivery, and evaluation. |
| BC Trauma Registry                     | Provides data collection, reporting and support of research and quality initiatives related to trauma care.   |

| Registry/Dataset                                 | Purpose  |
|--|--|
| BCCH's Biobank                                   | The mission of the BCCH BioBank is to provide a comprehensive service for the collection, processing, storage, rapid access and retrieval of biospecimens and clinical information for research projects using a professional and compassionate approach to patient consenting that adheres to the highest standards of research ethics and patient privacy. A single biospecimen from one patient has the ability to fuel numerous research projects, any one of which might lead to an important medical breakthrough. BC Children's Hospital BioBank collects samples from patients at both BC Children's Hospital and BC Women's Hospital. |
| Cervical Cancer Screening<br>Database            | A population based clinical system for cervical cancer screening as well as a lab system for all gynaecological cytology performed by the Provincial lab.  |
| Hereditary Cancer Program                        | The Hereditary Cancer Program is part of the BC Cancer Agency. The program offers services to families and individuals across British Columbia and the Yukon. Services include genetic counselling and information about cancer screening. People at risk of hereditary cancer may also be offered genetic testing.  |
| PREDICT  | PREDICT—Personal Response Determinants in Cancer Therapy is a unique centre-wide research project that has embedded a research culture into the day to day clinical care activities of the BC Cancer Agency's Vancouver Island Centre (VIC).   |
|  | <ol> <li>The goals of PREDICT are to:</li> <li>Create a population-scale biobank of blood samples obtained prior to initiation of systemic therapy from 20,000 new cancer patients;</li> </ol>   |
|  | Obtain permission from all new patients to be contacted to participate in future research projects, overcoming ethical and logistical hurdles to translational health research; and  |
|  | 3. Engage 75% of new patients and staff at the VIC in a common research endeavor that changes the culture of a cancer centre.  |
|  | PREDICT provides a unique platform to support specific research into host factors, such as the patient's immune system and adverse reactions to therapy, that influence the outcome of cancer therapies.   |
| PICNET   | Provincial Infection Control Network of BC's aim is to to reduce healthcare-associated infections in BC healthcare facilities. Key areas of focus are surveillance, evidence-based guidelines, and education.  |
| PROMIS-BC Renal Agency/<br>Transplant            | Patient Records and Outcome Management Information System – is the renal care community's clinical information system. With data collected from the 39 renal units in British Columbia, PROMIS supports: Individual patient care management; Renal unit management; Continuous quality improvement and research; Outcomes-based planning. PROMIS database is used as a source of important epidemiological data in support of clinical trials and for assessing new therapies.   |
| Screening Mammography Database (SMP)             | Clinical system for scheduling, reporting and tracking of screening mammography exams.   |
| BCEHS Resuscitation<br>Outcomes Consortium (ROC) | The Resuscitation Outcomes Consortium (ROC) was created to conduct clinical research in the areas of cardiopulmonary resuscitation and traumatic injury. ROC consists of 10 Regional Clinical Centers (RCCs), one satellite site and a Data and Coordinating Center (DCC) that will provide the necessary infrastructure to conduct multiple collaborative trials to aid rapid translation of promising scientific and clinical advances to improve resuscitation outcomes.  |
| Surgical Patient Registry (SPR)                  | SPR is a provincial program involving the five regional Health Authorities, the Provincial Health Services Authority (PHSA) and the Ministry of Health (MoH). SPR tracks patients waiting for surgery in British Columbia and provides information to evaluate and monitor surgical wait times in the province.  |
| Tumour Tissue Repository<br>(TTR)                | TTR is a provincial resource to support translational cancer research at the BCCA, across Canada and internationally. The TTR is a state of the art tumour bank that collects tissues, blood, and clinical information and processes these to create anonymous cases that can be studied by cancer researchers to understand how cancer develops, how it grows, how it spreads, and how it responds to treatment.  |

# **Supporting Research Activities**

For FY 2016-17, eleven (11) out of the fifteen (15), or 73% of registries/datasets are used for the purpose of research as defined by UBC (see Glossary, page 87). In addition, respondents were asked to identify other activities they provide in support of research. Table 17 lists the support activities by

registry/dataset and shows the number of times in the past three fiscal years that a registry has provided a particular support activity. These research support activities are ranked from most provided to least over the three-year period.

TABLE 17 Research Activities Supported by Registries and Datasets

| December 2   | cer    | Cardiac | Cervical | Perinatal | PICNet | PREDICT | a     | <b>a</b> | ~   | Transplant | ıma    |     | Biobank | BCEHS/ROC | Generations | Hereditary | Grand Total |
|--|--------|---------|----------|-----------|--------|---------|-------|----------|-----|------------|--------|-----|---------|-----------|-------------|------------|-------------|
| Research Support<br>Activity   | Cancer | Car     | Cer      | Peri      | PIC    | PRE     | Renal | SMP      | SPR | Trar       | Trauma | TTR | Bioł    | BCI       | Gen         | Her        | Gra         |
| Support in managing and linking data   | 3      | 3       | 3        | 2         |        | 3       | 2     | 3        | 2   | 1          | 2      | 3   | 2       |           | 1           |            | 30          |
| Support in designing research studies  | 3      | 2       | 3        | 3         |        | 3       | 2     | 3        |     | 1          | 1      | 3   | 2       | 2         |             |            | 28          |
| Support in ensuring studies meet regulatory standards  | 3      | 3       | 1        | 2         |        | 3       | 2     | 2        | 1   |            | 1      | 3   | 1       | 1         |             |            | 23          |
| Assist in identifying knowledge gaps and improvement needs                                     |        | 3       | 3        | 3         | 2      |         | 2     | 3        |     | 1          | 3      |     |         | 1         |             | 1          | 22          |
| Facilitate communication to identify pertinent research question                               |        | 3       | 3        | 2         | 2      |         | 2     | 3        | 2   | 1          | 3      |     |         | 1         |             |            | 22          |
| Provide specialized and multidisciplinary methodological expertise                             | 3      | 3       |          | 1         |        | 2       | 2     |          |     | 1          | 1      | 2   |         | 1         |             |            | 16          |
| Support in conducting biostatistical analysis  |        | 3       | 1        | 1         |        |         | 2     | 2        | 1   | 1          | 2      |     |         | 2         |             |            | 15          |
| Teaching and hands on training for the above   |        |         |          | 2         |        | 3       | 1     |          |     |            |        | 3   |         | 1         |             |            | 10          |
| Application of new technical capabilities to provide more timely access to wider range of data |        | 1       |          | 2         |        |         | 2     |          |     |            | 3      |     | 1       |           |             |            | 9           |
| Other  | 2      |         |          |           |        |         |       |          |     |            |        |     | 1       |           | 2           |            | 5           |
| Not used to support research activities  |        |         |          |           | 1      |         |       |          | 1   |            |        |     |         |           |             |            | 2           |
| Grand Total  | 14     | 21      | 14       | 18        | 5      | 14      | 17    | 16       | 7   | 6          | 16     | 14  | 7       | 9         | 3           | 1          | 182         |

Respondents were asked if they submit data to external organizations for the purposes of research. See Table 18 for the breakdown of data set type by registry/dataset for FY 2016-17. This table lists the type of external data set and

shows the number of times in the past three years that the registry has submitted data. The type of dataset is ranked from most submitted to least.

TABLE 18 Provision of Data to external Data Sets by Registry

| Type of External Data Set                 | Cancer | Cardiac | Cervical | Perinatal | PICNet | PREDICT | Renal | SMP | SPR | Transplant | Trauma | TTR | Biobank | BCEHS/ROC | Generations | Hereditary | Grand Total |
|---|--------|---------|----------|-----------|--------|---------|-------|-----|-----|------------|--------|-----|---------|-----------|-------------|------------|-------------|
| Pan Canadian dataset                      | 3      |         |          |           |        |         | 3     | 3   | 3   | 1          | 2      | 3   |         | 1         | 1           |            | 20          |
| Data Not Submitted to<br>Any Organization |        | 1       | 3        |           | 3      | 2       |       |     |     |            |        |     | 1       |           |             | 1          | 11          |
| Other                                     | 3      | 2       |          | 2         |        |         |       | 1   |     |            | 1      |     | 1       |           |             |            | 10          |
| Cross feeding within PHSA                 | 2      | 2       |          | 1         |        |         | 2     |     |     | 1          |        |     |         |           |             |            | 8           |
| Provincial data                           |        | 2       |          | 1         |        |         | 1     |     | 1   |            | 1      |     |         |           | 1           |            | 7           |
| International dataset                     | 3      |         |          |           |        |         | 2     |     |     | 1          |        |     |         | 1         |             |            | 7           |
| Grand Total                               | 11     | 7       | 3        | 4         | 3      | 2       | 8     | 4   | 4   | 3          | 4      | 3   | 2       | 2         | 2           | 1          | 63          |

Names of the external datasets include:

Provincial: ICV Health—BC Centre for Improved Cardiovascular Health

Surgical Patient Registry (SPR) Completed Surgical Cases—Ministry of Health

Population Data BC Spinal Cord Registry Statistics Canada

Pan Canadian: Canadian Cancer Registry—Statistics Canada

Canadian Organ Replacement Registry (CORR)

Canadian Ovarian Experimental Unified Resource (COEUR)—Terry Fox Research Institute

Canadian Partnership for Tomorrow Project—Canadian Partnership Against Cancer

Canadian Resuscitation Outcomes Consortium

Public Health Agency of Canada (Canadian Breast Cancer Screening Database)

National Trauma Registry

Pediatric Trauma Care Quality Indicators—London Health Sciences

Canadian Joint Replacement Registry—CIHI
Canadian Tissue Repository Network (CTRNet)

International: North American Association of Central Cancer Registries (NAACCR)

National Pediatric Trauma Injury-NIH

International Agency for Research on Cancer (IARC - a division of the World Health Organization)

International Society for Heart & Lung Transplant (ISHLT)

Resuscitation Outcomes Consortium (RoC)\*

Chronic Kidney Disease Prognosis Consortium (CKD-PC)

Peritoneal Dialysis Outcome and Practice Patterns Study (PDOPPS)

#### **Nature of Research Activities**

CIHR (Canadian Institutes of Health Research) categorizes health research into four broad themes: biomedical research, clinical research, health services research (research respecting health systems and services); and social, cultural, environmental and population health. Research pursued

using the registries/datasets above are categorized in Figure 54. Access requests are summarized in Figure 55. For examples of the types of research questions posed by researchers, please see Appendix 1.

FIGURE 54 Ranking of Predominant Nature of Research Questions Using Data from the Registries/Datasets

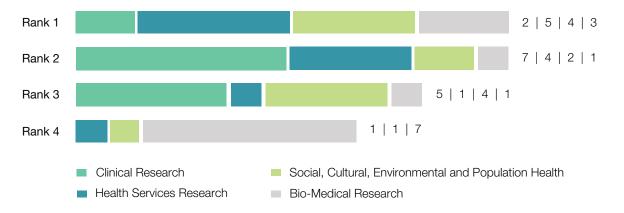
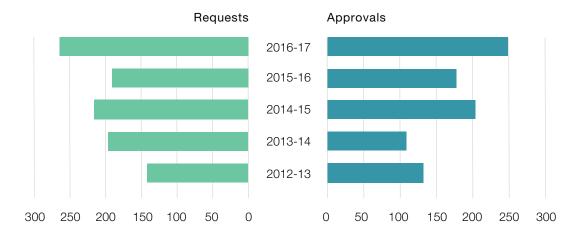


FIGURE 55 Research Access Requests and Approvals from Registry/Dataset by Fiscal Year



<sup>\*</sup>ROC include 4 distinct data sets; Cardiac Clinical Trials, Trauma Clinical Trials, Cardiac Arrest Registry and Trauma Registry.

In addition, BCEHS manages a data set for ongoing research; the Red Blood Cell Products Pilot Project. BC Emergency Health Services is mainly a health service delivery agency whose mandate includes the production of knowledge in the patient populations they serve.

#### **Research Benefits**

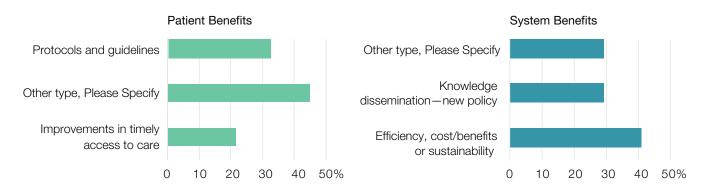
Again, this year, data stewards were asked to classify the

research benefits identified for FY 2016-17 into two distinct categories; Patient Benefits and System Benefits. See below for further detail on benefit types. Benefits resulting from research activities are 56% attributed towards System Benefits and 44% towards Patient Benefits.

Figure 56 shows the percentages for each benefit category as a result of the registry and dataset usage for FY 2016-17.

| Benefit Type     | Benefit Sub-type                           |  |  |  |  |  |  |
|------------------|--|--|--|--|--|--|--|
| Patient Benefit: | Delay of disease progression/survival.     |  |  |  |  |  |  |
|                  | Access to new treatment/technology         |  |  |  |  |  |  |
|                  | Protocols and guidelines                   |  |  |  |  |  |  |
|                  | Improvements in timely access to care      |  |  |  |  |  |  |
|                  | Other                                      |  |  |  |  |  |  |
| System Benefits: | Process of care: standardization           |  |  |  |  |  |  |
|                  | Process of care: protocol implementation   |  |  |  |  |  |  |
|                  | Efficiency-cost/benefits or sustainability |  |  |  |  |  |  |
|                  | Knowledge dissemination: new policy        |  |  |  |  |  |  |
|                  | Resource improvements: workforce           |  |  |  |  |  |  |
|                  | Other                                      |  |  |  |  |  |  |

FIGURE 56 Percentage of Benefit Sub-type by Type for FY 2016-17



A sample of patient and/or system benefits that were quantified, identified, or attained in FY 2016-17 that resulted from research based on the registry or dataset is excerpted below.

**TABLE 19** Registry/Dataset Patient and System Benefits

| BC Cancer Registry                    | The HPV FOCAL study has been a user of cervical cancer incidence data from the Registry and has published many articles in the past couple of years that are being used as an evidence base in and outside BC for new screening policy for cervical cancer.  | System: Knowledge dissemination-<br>new policy      |
|---------------------------------------|--|---|
|                                       | A study on cancer incidence, mortality and survival in BC First Nations and non-First Nations people has provided baseline information for cancer control efforts for First Nations people in BC. This information was generated as a partnership between BC Cancer and First Nations Health Authority and will be used for strategy development.  | System: Other type, Please Specify                  |
| BC Trauma Registry                    | Trauma team activation criteria reviewed.  | Patient: Improvements in timely access to care      |
|                                       | Understanding if collecting patient outcomes is feasible.  | System: Other type, Please Specify                  |
|                                       | Proving that a trauma service improves patient outcomes  | System: Efficiency, cost/benefits or sustainability |
|                                       | Proving that round the clock radiology for large trauma centres improves patient care  | System: Efficiency, cost/benefits or sustainability |
| Cervical Cancer<br>Screening Database | Similar to the BC Cancer Registry, the data from the CCSP support the HPV FOCAL trial which is a high impact clinical trial funded by CIHR which is building evidence to direct new screening policy in BC and Canada for cervical cancer. This project has led to significant manuscripts, presentations and evidence around the use of HPV testing for screening.  | System: Knowledge dissemination-<br>new policy      |
|                                       | Data from the CCSP have supported development of the OncoSIm models that permit cost-benefit analyses for potential screening strategies for Canada. These models are available to cancer control groups in Canada aiming to assess impacts of different screening models for cancer.  | System: Efficiency, cost/benefits or sustainability |
|                                       | Evaluation of policy: Some data from CCSP have been used in early assessments of the effectiveness of the HPV vaccine in BC. Further work continues in this area however an initial paper has been published and an approved data application will further this evaluation of a provincial program.  | System: Other type, Please Specify                  |
| PREDICT                               | The PREDICT project has provided direct (~540) opportunities to patients to contribute to and partner with our research project.   | Patient: Other type, Please Specify                 |
| Screening<br>Mammography<br>Database  | A successful clinical trial which operated within SMPBC using data from this database was both published this year as well as led to the implementation of an intervention to improve return rates for women in the screening program. This intervention involved primary care physicians signing letters to remind overdue women to have their mammograms and was shown to significantly improve return of overdue women. | System: Process of care-protocol implementation     |
|                                       | As with the Cervical Cancer Screening Database, data from SMPBC have supported the development of OncoSIm models that are made available to cancer control experts in Canada via a web-based platform. These models permit cost-benefit analyses for different screening strategies to be undertaken to inform potential screening strategy development.   | System: Efficiency, cost/benefits or sustainability |

| Tumour Tissue<br>Repository              | The TTR has provided direct (~300) opportunities to patients to contribute to and partner with our research program.  | Patient: Other type, Please Specify                 |
|--|---|---|
|  | The TTR has supported BCCA researchers to secure grant funding for research programs in addition to generating high profile/impact research publications.   | System: Other type, Please Specify                  |
|  | The TTR continues its partnership with the Canadian Tissue Repository Network and UBC's Office of Biobank Education and Research to support the work of the Biobank Resource Centre in assisting biobankers. TTR support included: 1) Continuing assistance with the development of biobank education modules. 2) Assistance with program testing ahead of the launch of the Biobank Registration and Certification Program for researchers and biobankers internationally. | System: Other type, Please Specify                  |
| BC Children's<br>BioBank                 | The BioBank provides a method of recruiting patients and collecting biological samples for future research. This approach allows for a streamlined collection of samples and subsequent preparation of the samples for research which is cost effective as compared with each PI paying individually for each step of the process, ie there is economy of scale.  | System: Efficiency, cost/benefits or sustainability |
|  | The BioBank provides a resource which is rich in high quality samples with annotated data about the collection and timing of processing. BioBank staff are specialist in specimen processing and preservation and the research workforce benefits from having access to high quality and reliable samples.  | System: Resource improvements-workforce             |
|  | Research done using biobank samples will ultimately lead to improved knowledge dissemination and potentially new treatments.  | System: Knowledge dissemination-<br>new policy      |
|  | Dissemination of the role of the BioBank has the potential to influence policy change in terms of where researchers can access samples for their research.  | System: Knowledge dissemination-<br>new policy      |
| BCAS/ROC —<br>Cardiac Arrest<br>Registry | Data on non-traumatic ambulance treated adult OHCA from 2006 to 2016 in Victoria, Vancouver, FV and Kelowna review for survival to discharge looking for trends in baseline characteristics   | System: Process of care-standardization             |
|  | Out of Hospital cardiac arrest in BC; Identifying care gaps and opportunities to improve long-term outcomes   | Patient: Protocols and guidelines                   |
| BC Generations<br>Project                | Access to a large cohort of healthy individuals for research projects.  | System: Efficiency, cost/benefits or sustainability |
|  | Potential for early detection and prevention  | Patient: Other type, Please Specify                 |
| PROMIS—Renal                             | The following research project is the 1st project to demonstrate impact of general infections on progression of CKD patients before dialysis: "Infection Rates in CKD is an Independent Risk Factor for Mortality and Progression to Dialysis using the CanPREDDICT Cohort."  | Patient: Delay of disease progression/survival      |
|  | The following evaluation, completely based on PROMIS data, demonstrated utility of new home HD machine on maintaining patients at home on independent dialysis, both from patients and system perspective: "Clinical and economic evaluation of a twelve-month pilot of the NxStage System One within an established Home Hemodialysis program"   | Patient: Access to new treatment/<br>technology     |
|  | Because of the Provincial Registry patients with rare disease have opportunity to participate in clinical trials and observational studies; examples ADPKD, Alport and GN.  | Patient: Other type, Please Specify                 |

|                              | Deprescribing: PROMIS data were used to examine prescribing practices in BC dialysis patients and identify opportunities to reduce and stop use of multiple medications among elderly dialysis patients.   | Patient: Protocols and guidelines                   |
|------------------------------|--|---|
|                              | The registries of GN and ADPKD patients (i.e. PROMIS sub-registries of rare CKDs) enabled evaluation of implementation of general drug formularies and specific medications. Our research demonstrated cost benefits of Provincial formulary for immunosuppression drugs in GN patients and safety of Tolvaptan, a novel drug for ADPKD. | System: Efficiency, cost/benefits or sustainability |
|                              | Linked data PROMIS and HeartIS data used to explore differences btw renal outcomes in CKD patients after cardiac procedures.   |   |
|                              | PROMIS implementation analysis of PROMs (ESAS) data demonstrated value of province-wide implementation of PROMs and need for EOL care standardization and coordination.  |   |
| Hereditary Cancer<br>Program | Evaluation of genetic testing performance allows for the appropriate statistics related to variant detection rates to be used in genetic counselling.  | System: Knowledge dissemination-<br>new policy      |
|                              | Evaluation of genetic testing performance allows the Hereditary Cancer Program to make policy decisions regarding genetic testing criteria in-part informed by local data.   | Patient: Protocols and guidelines                   |
|                              | Evaluation of new models of genetic testing allows the Hereditary Cancer Program to assess new processes that improve timely access to care, while ensuring clinical standards are maintained.   | Patient: Improvements in timely access to care      |

# Appendix 1: Example Research Questions by Registry/Dataset

| BC Cancer Registry       | The Economics of Personalized OncoGenomics in BC: Cost-effectiveness of precision medicine oncogenomic care in BC.   |
|--------------------------|--|
|                          | The addition of chemotherapy to adjuvant management of patients with stage I endometrial cancer treated with curative intent surgery - the impact on recurrence and survival.          |
|                          | What are the prognostic implications of tumor-infiltrating lymphocytes (TIL) in prostate cancer and how does their presence correlate with tumor antigen load?                         |
|                          | Evaluation of the risk of relapse of patients with advanced stage melanoma at event-free survival time points.   |
|                          | The real-world safety and effectiveness of Bevacizumab in patients with metastatic colorectal cancer.  |
|                          | Triple negative breast cancer: a BC experience in outcomes and BRCA germline mutation status.  |
|                          | Treatment outcomes and risk factors in patients with indolent LY treated in BC.  |
|                          | Does the extent of chemotherapy, radiation, and surgery vary for breast cancers detected by first mammogram screen, subsequent screens, and non-screen methods?                        |
|                          | A non-interventional retrospective review of CNS metastases in EGFR mutation positive NSCLC in the province of British Columbia: Patterns of treatment and health resource utilization |
|                          | Real-world Outcomes of adjuvant ddACT, ACT and FEC-D. A Multicenter retrospective analysis   |
| BC Cardiac Registry      | What are the temporal trends in Heart Failure Hospitalizations and Outcomes in BC?   |
|                          | How do you avoid cardiovascular events in BC?  |
|                          | What is the impact of endocrinology consultation service on outcomes in patients with diabetes undergoing CABG?  |
|                          | What is the quantitative assessment of coronary artery burden of disease in South Asian patients?  |
|                          | What is the prevalence of pulmonary vein electrical connection after atrial fib ablation?  |
|                          | What are the clinical pathways of patients with cardiomyopathy-echocardiology and ICD patterns?  |
|                          | What are the factors associated with dysphagia in post op cardiac surgery patients?  |
|                          | What is the prevalence of coronary artery disease and left ventricular dysfunction in individuals with cystic fibrosis undergoing lung transplant?                                     |
|                          | What is the comparative effectiveness of PCI and CABG in BC?   |
| BC Trauma Registry       | RCH Trauma Team activation response and lapse time   |
|                          | Abbotsford Hospital impact of a trauma service   |
|                          | Outcomes after Hospitalization for Major Trauma: A Feasibility Study   |
|                          | Retrospective Review of Trauma Patient Outcomes  |
|                          | Burden of equestrian injuries in BC  |
|                          | Clinical Impact of 247 On-Site Staff Radiologist Coverage in the Vancouver General Hospital Emergency  |
|                          | Surgeon vs non-surgeon Trauma Team Leader a multi-centre cohort study  |
| Cervical Cancer          | Evaluation of HPV prevalence and genotype in a cohort of BC Invasive cervical cancer cases.  |
| Screening Database       | HPV FOCAL: Predicting effects of changes from Pap to human papillomavirus screening and of changes in screening participation  |
|                          | HPV FOCAL: Disease detection and resource use in the safety and control arms of the HPV FOCAL cervical cancer screening trial  |
|                          | Patterns of Cervical Cancer Incidence in 2014  |
| Screening<br>Mammography | Does the extent of chemotherapy, radiation, and surgery vary for breast cancers detected by first mammogram screen, subsequent screens, and non-screen methods?                        |
| Database                 | Modeling the Development and Progression of Breast Cancer Using Computer Aided Detection (CAD).  |
|                          | Outcomes of female stage I-III breast cancer receiving dose dense ACT and FEC-D chemotherapy.  |
|                          | Validation of Volumetric Breast Density as an Imaging Biomarker for Predicting Breast Cancer Risk and Prognostication  |

| Tumaur Tianua               | Handhald Multiphaton Imaging Daviso for Datasting Oral Consor   |
|-----------------------------|---|
| Tumour Tissue<br>Repository | Handheld Multiphoton Imaging Device for Detecting Oral Cancer  Creating a Pan Oral Atlantation of Canatara and Expression Diversity in Healthy Individuals  |
|                             | Creating a Pan-Omic Atlas of Genotype and Expression Diversity in Healthy Individuals  Multidisciplinary Ovarian Cancer Outcomes Group (MOCOG) study of tumor infiltrating lymphocytes in ovarian |
|                             | cancer tissues  |
|                             | Determining the signaling properties of tumor-infiltrating lymphocytes using a novel method of in situ stimulation.   |
|                             | Dissecting Genomic Heterogeneity in Metastatic Breast Tumours   |
|                             | A pan-Canadian platform for the development of biomarker-driven subtype specific management of ovarian carcinoma  |
|                             | Tumour Tissue Repository and Re-targeting virus-specific CD8+ T cells to recognize and attack tumours (BCCA-TTR-CEF-OV) Project   |
| BC Children's BioBank       | Can we use MRD positive samples as a way of identifying and evaluating potential relapse clones?  |
|                             | Monitoring serum calreticulin in pediatric ALL as a marker for positive chemotherapeutic response   |
|                             | Proteins and their modification in childhood cancer   |
|                             | Assessment of alternate P-selectin ligand expression in human   |
|                             | Case Study of a Child with a Rare Autoinflammatory Condition  |
|                             | Circulating Cell-Free DNA Analysis in Children with Solid Tumors Administered with Granulocyte Colony Stimulating Factor  |
| BCAS/ROC-Cardiac            | Targeted temperature management after out-of-hospital cardiac arrest: who, when, why, and how?  |
| Arrest Registry             | Amiodarone, Lidocaine, or Placebo in Out-of-Hospital Cardiac Arrest   |
|                             | Potential Candidates for a Structured Canadian ECPR Program for Out-of-Hospital cardiac Arrest  |
|                             | Relationship between Time-to-ROSC and Survival in Out-of-hospital Cardiac Arrest ECPR Candidates: When is the Best Time to Consider Transport to Hospital?  |
|                             | Comparing the prognosis of those with initial shockable and non-shockable rhythms with increasing durations of CPR: Informing minimum durations of resuscitation                                  |
|                             | The association of maximum Troponin values post out-of-hospital cardiac arrest with electrocardiographic findings, cardiac reperfusion procedures and survival to discharge                       |
|                             | Analysis of cardiac arrest process and outcomes related to ethnicity  |
|                             | Analysis of outcomes in BC cases entered into the continuous vs interrupted chest compression trial: influence on BC CPR policy   |
|                             | Linking BC provincial data sets to evaluate pre-arrest predictors and post arrest care, treatments and long-term survival   |
|                             | Comparison of outcomes in a new rapid diversion policy for hospital initiated Extracorporeal CPR  |
| BC Generations Project      | Effects of smoking Cessation after cancer diagnosis   |
|                             | Evaluating Causal Relationships between Built Environment Characteristics, Health Care Utilization Patterns and Costs in BC   |
|                             | Sociodemographic, dental utilization and oral cancer awareness in BC.   |
|                             | Understanding the causes and the development of chronic diseases such as heart disease, stroke, dementia and cancer   |
|                             | A novel metabolic approach to study modifiable risk factors for cancer  |
|                             | Determining whether it is possible to detect early signs of cancer through a simple blood test.   |
|                             | Predicting Cancer Susceptibility via Immune Status  |
| PROMIS-Renal                | An examination of adherence to medical follow-up by living kidney donors.   |
|                             | Clinical and economic evaluation of a twelve-month pilot of the NxStage System One within an established Home Hemodialysis program  |
|                             | Factors influencing the timing of RRT initiation and choice of modality in children   |
|                             | Long term outcomes of acute kidney injury in a population under nephrology review with protocolized follow-up   |
|                             | 25.3 term states not of additional injury in a population driving notional visit protocolized follow up   |

Prescribing Practices in BC Dialysis Patients

GN Formulary: Cost of Immunosuppression

Natural History of Disease Study in Alport Syndrome Patients

Effect of cinacalcet use and mineral bone disorder in BC dialysis population

High patient turnover in independent dialysis limits the utility of prevalence-based program targets

Cancer in Kidney Disease

Glomerulonephritis does not confer increased risk of cardiovascular events in patients with CKD

#### **BC** Perinatal Database Registry

What are the spatiotemporal trends in air pollution and autism diagnoses from 2004–2014 in Metro Vancouver?

To develop and validate an algorithm for case ascertainment of ASD using readily available health and administrative data. To estimate the prevalence of ASD in British Columbia and to look at changes in this prevalence over time. To estimate the rate of fetal exposure to exogenous oxytocin in British Columbia and to look at changes in this rate over time. To test the hypothesis that the frequency of ASD diagnoses is greater among children who are exposed to exogenous oxytocin in labour than among those who are not, first through a population-based retrospective cohort study and then through a case-control study of matched sibling pairs who are discordant for ASD.

To evaluate the risk of the complications across the skin, joint and bowel diseases of interest compared to the general population, after adjusting for appropriate confounders. Within each skin, joint and bowel disease, to determine the role and relative contribution of risk factors of interest, inflammatory disease activity, and its treatment to the development or prevention of complications; and to determine if selected measures of disease activity and treatments make a contribution to the development or prevention of complications across different inflammatory conditions.

We hypothesize that Nursing Family Partnership will improve the primary and secondary outcomes considering both statistical significance and clinical importance — with effects mediated and moderated by a number of variables, and with economic benefits also being postulated.

Determine diabetes therapy treatment patterns over time, and evaluate factors associated with different treatment patterns (e.g. comorbidities, coverage policies, adherence, etc.). Identify care gaps and determine what patient/policy/practice factors contribute to gaps in care; Calculate the overall economic burden of diabetes in BC; Identify strategies to improve patient outcomes and reduce the economic burden of diabetes.

To compare the asthma evolution of offspring of pregnant mothers with asthma who are poorly vs. adequately controlled during pregnancy.

The study aims to capture long term developmental outcomes of children who are HIV-exposed and uninfected (HEU) born between 1990 and 2012 to HIV-infected mothers in British Columbia, Canada.

Describe pre- and perinatal use of biologics by quantifying prevalence and describing patterns of biologics use in the two years before pregnancy, during pregnancy, and one year after pregnancy; Assess adverse maternal outcomes associated with pre- and perinatal use of biologics by quantifying the relative risk of adverse pregnancy-related outcomes between the exposed group, the unexposed disease-matched group, and the non-diseased control group; Assess adverse neonatal outcomes associated with pre- and perinatal use of biologics by quantifying the relative risk of adverse neonatal outcomes between the exposed (in utero) group, the unexposed maternal disease-matched group, and the non-diseased control group;

### **Hereditary Cancer** Program

Understanding Mutation detection rates using gene panels

Evaluation of a new type of service delivery

Improved diagnosis of hereditary cancer

Evaluation of tumor sequencing

Outcome analysis based on mutation status

Assessment of universal lynch screening

Assessment of improved diagnostic parrafin sequencing techniques

Assessment of pathology immunohistochemistry to improve diagnosis

### Appendix 2: Framework for PHSA Research Metrics

#### Indicator: Producing and Advancing Knowledge

This category includes measures reflecting discoveries/new knowledge, and contributions to scientific literature.

- a. Total annual grant awards by agency/research entity and PHSA
- b. Total annual external grant awards by agency/research entity, identified by major funding categories (e.g., tri-council, provincial, Genome Canada/BC, international, private sector, etc.)
- Annual grant application success rate by agency/research entity and PHSA
- Total # Publications
- Citations

### 2. Indicator: Building Research Capacity

This category includes measures reflecting enhancements to both human resource and infrastructure capacity.

- a. Total # trainees by agency/research entity
- b. Scholarships/fellowships by agency/research entity
- Total # researchers by agency/research entity
- Infrastructure investments
  - i. E.g. Hospital research fund, BCCHR, capital projects etc.
  - ii. Databases (patient, tissue) etc.
- Indirect Costs Program

### **Indicator: Achieving Economic Benefits and Innovation**

This category includes measures reflecting commercialization of discoveries, revenues and other economic benefits resulting from discoveries, and general impacts on the BC economy.

- a. # Intellectual property disclosures, patents by agency/research entity
- b. Licenses, royalty income, spin-off companies
- c. New research hires to agency/research entity job creation?
- d. Policy initiatives

### **Indicator: Advancing Health and Policy Benefits**

This category includes measures reflecting individual and population health impacts of research in prevention, diagnosis and treatment.

- Clinical trials (translational research)/patient outcome data
- New clinical guidelines/patient outcome data
- New drugs funded/patient outcome data
- d. Policy initiatives/patient outcome data

## Appendix 3: Research Metrics Working Group Membership\*

### **Ellen Chesney**

Chief Administrative Officer - Research, PHSA

### Kathryn Dewar, PhD

Senior Research Manager, Women's Health Research Institute (WHRI)

### Ognjenka Djurdjev

Corporate Director, Performance Measurement & Reporting, PHSA

### **Nur Eisma**

UBC/C&W Coordinator Pre & Post Awards

### **Karin Jackson**

Director, Planning, Performance Management & Research BC Mental Health & Substance Use Services

### Karen Hagan

Grants Advisor, Office of Research Facilitation, BC Cancer Agency

#### Phoebe Lu

Director, Research Services, BC Children's Hospital Research Institute

### **Beth Palacios**

Consultant, Performance Measurement & Reporting, PHSA

### **Priscilla Vuong**

Research Development Unit Manager, BC/UBC Centre for Disease Control

### Julie Wei

BC Emergency Health Services

\*As of September, 2016

## Appendix 4: Glossary

|  | GLOSSARY   |
|--|--|
| Term   | Description [data source]  |
| Metric Definitions   |  |
| Metrics 1ab, 2b Total annual grant awards, Total annual external grant awards by major funding categories by agency or research entity | Total Annual Award (\$) for Grants, Awards and Contracts by Funding Source  [RISe annual file provided by UBC Office of Research Services]   |
| Metric 1c<br>Annual grant application<br>success rate by agency/<br>research entity. Added in FY<br>09–10                              | Success rates for two CIHR operating grant competitions (March and September of applicable year) for BCCA and BCCHR, BCMHSUS and WHRI.  [CIHR website for National results; Agency results self-reported on the excel data collection form]  |
| Metric 1d Total # of Publications Added in FY 10–11; Category addition in FY 11–12   | Total number (of publications, not authors) published within applicable fiscal year meeting the following criteria: Book, book chapter, reports produced for the government, peer-reviewed publication inclusive of published journal articles, case reports, essays, literature reviews, e-journals and monographs. Excluded = abstracts, editorials, summaries, letters to the Editor, epubs, in press and submitted publications.  [Agencies self-report utilizing SciVal to search Scopus utilizing researcher name; Agency inputs data on excel data collection form]   |
| Metric 2a Total number of trainees by agency/research entity   | Total Number (head count, not FTE) of Research Trainees by Student Type. (Exclude clinical trainees who are supported during their brief research rotations.) Research trainees counted will be any individuals who are primarily supervised by a researcher affiliated with the reporting unit, during all or a portion of the reporting year.  [Agencies manually request trainee statistics from individual investigators and input data on excel data collection form]   |
| Metric 2c Total number of researchers by agency/research entity  | List of Researcher Names including Research definition (This metric is to be collected based on BCCHRI methodology category types wherever possible, if not available in that format, please designate your category as "5" and add your research definition in the space provided.) Added in FY 11–12 is a column to collect whether a researcher is a shared resource or 100% attributable to a specific agency.   |
|  | [Previous year's researchers are provided to each agency from the researcher database in excel; Agencies provide additions, deletions, changes on excel data collection form]  |
| Metric 2d Infrastructure Investments: Major CFI Infrastructure Grants (Added FY 10–11)   | Total FY \$ for Leading Edge Fund (LEF)/New Initiatives Fund (NIF) awards from Canada Foundation for Innovation. LEF projects sustain and further enhance the most advanced research and technology development efforts already supported by past CFI investments. LEF projects build on existing areas of research priority where institutions have a competitive advantage and a proven track record in enhancing Canada's science and technology capacity. NIF projects build Canada's capacity in new, promising areas of research and technology development. Also included in these amounts are the matching funds (industry, educational, charity, etc.) to these awards. Excluded from these amounts are \$'s associated with the Infrastructure Operating Fund (IOF) or Leaders Opportunity Fund (LOF) from CFI. These get reported under Infrastructure—HR awards and operating grant categories respectively. |
| Maria  | [RISe annual file provided by UBC Office of Research Services]   |
| Metric 2e<br>Indirect Costs Program<br>grants (Added FY 12–13)   | A federally funded grant to Canadian post-secondary institutions to help pay the indirect costs of research (e.g. salaries for research administrative staff, administrative costs associated with patent activities, maintenance of lab space). These annual grants are based on a formula related to tri-council award amounts (CIHR, NSERC, and SSHRC) and are paid to the research institutes based on a formal revenue sharing agreement. Due to how UBC is now reporting revenue precipitated by policy changes of the CAUBO (Canadian Association of University Business Officers), PHSA includes revenue related to the Indirect Costs Program (ICP).  |
|  | [RISe annual file provided by UBC Office of Research Services]   |

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| Term   | Description [data source]  |  |
| Metric 3a # of intellectual property disclosures, patents by agency/research entity  | Total number of Invention Disclosure (internal documents), provisional patent and PCT applications by fiscal year.  [BCTDO (for BCCA) and UILO (all other agencies) complete the excel data collection form]   |  |
| Metric 3b Licenses, royalty income and # spin-off companies (Revised FY 10/11) (Revised Net Licensing Rev definitions in FY 2013–14) | Total number of active license/assignment agreements and spin-off companies. List the names of all active spin-off companies. These numbers represent cumulative totals from year to year and are no longer reported by region. IP related revenue shall follow the UILO (University-Industry Liaison Office) definitions from FY 2010–11 forward.  Definitions:  Gross licensing revenue = Royalties + Equity Liquidated + Option Fees + License Fees + License Management + Technology Assignment;  Royalties: royalty payments including minimum annual royalty payments  License Fees: upfront payments, milestone payments and other payments associated with the license  License Management: legal fees incurred by TDO (Technology Development Office) or UILO relating to |  |
|  | Total TDO Expenses for patenting and legal costs  Expenses for Licensed IP: patenting, legal and related costs associated with licensed IP   |  |
|  | Realized revenue per distribution agreements: revenue accrued to PHSA agency after distribution to inventors, obligations due to affiliated academic institutions, granting agencies and inventor departments.   |  |
|  | The revenue distribution varies by entity and will be noted in the narrative.  |  |
|  | Royalty, equity liquidated and licensee fees  When the UILO licenses technology to a company, the terms of the license typically include a requirement to pay a % royalty on product sales, an upfront license fee and an annual license maintenance fee. The UILO may also negotiate an equity component (company stock) as part of the license agreement. Under the licensing scenario, the University still owns the technology but is granting a license to a third party.   |  |
|  | Option Fees  |  |
|  | This relates to the scenario when a company desires an option on a technology (essentially reserving/holding the technology). These are usually short-term contracts that have a modest option fee.  |  |
|  | Technology Assignment  |  |
|  | This relates to the scenario when a company wishes to take ownership of the technology and in return pays an Assignment fee.   |  |
|  | [BCTDO (for BCCA) and UILO (all other agencies) complete the excel data collection form]   |  |
| Metric 4a<br>Clinical Trials   | Number of active trials and cumulative subject enrollment at the end of the year. Includes CT data for all PHSA and non-PHSA PIs using PHSA facilities and resources   |  |
| Source: Ethics Module for all REBs   |  |  |
| Funding Type Categories (co  | olumns)  |  |
| Funding Types/Grant Types  | The columns on worksheet 1ab, 2b that correspond to the funding types agreed to by the Research Metrics Working Group on July 22, 2009 and revised at the working group's direction in subsequent fiscal years.  |  |
| Salary Awards  |  |  |
| Faculty and other personnel support  | Dollar amount for FY for supported faculty salary awards including chairs.   |  |
| Trainee salary support   | Dollar amount for FY for supported trainee salary awards including trainee research allowances.  |  |
| Infrastructure Awards  |  |  |

|  | GLOSSARY  |
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| Term   | Description [data source]   |
| Human Resources  | Dollar amount for FY for Human Resource Infrastructure including Michael Smith Foundation for Health Research (MSFHR)—team start-up, team, research units, platforms, networks and institutional infrastructure, CFI Infrastructure Operating Fund (IOF) awards.  |
| Capital, Equipment,<br>Construction  | Dollar amount for FY for capital, equipment, or construction awards including BC Knowledge Development Fund (BCKDF), matched sources (charities, industry) and other large equipment grants. Excluded are Canada Foundation for Innovation (CFI) awards (see next category).  |
| Capital, Equipment,<br>Construction – Major CFI<br>(Added in FY 10–11)   | Dollar amount for FY for capital, equipment, or construction Major Canada Foundation for Innovation (CFI) awards for Leading Edge Fund (LEF)/New Initiatives Fund (NIF) awards. Also included in these amounts are the matching funds (industry, educational, charity, etc.) to these awards. Excluded are \$'s associated with the Infrastructure Operating Fund (IOF) or Leaders Opportunity Fund (LOF) from DFI. These get reported under Infrastructure - HR and Operating Grant categories respectively. (see Metric definition 2d for further detail)   |
| Operating Grants   |   |
| Operating or Project Operating Grants (not exclusive of the next three columns)                                  | Dollar amount for FY for operating or project operating grants including when the salary component is embedded in a grant; includes establishment grants; includes development grants.  |
| Clinical Trials (4a) (Definition clarified in FY 10-11)  | Dollar amount for FY for any research project that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes. Health related interventions include any intervention used to modify a biomedical or health-related outcome, for example drugs, surgical procedures, devices, behavioral treatments, dietary interventions, and process-of-care changes. Health outcomes include any biomedical or health related measures obtained in patients or participants, including pharmacokinetic measures and adverse events. |
| Clinical Trials (4a) (Definition clarified in FY 10-11)  | Dollar amount for FY for research involving a new laboratory technique or process, e.g. a new more cost effective processing for a genetic diagnostic test, or a new tissue preparation process, etc. Trials that may use clinical material but do not directly involve patients in the research or involve a risk to the patients (may involve their tissue or blood samples however).   |
| Grant in Aid   | Dollar amount for FY for Grant-in-aid awards (Broad topic but not directed).  |
|  | A Grant-in-Aid is essentially a donation to one or more researchers, normally to conduct research in an area that is of mutual interest to both the donor and the researcher(s). These grants are normally in the form of a one-page letter addressed to a researcher and signed by the donor, and accompanied by the grant funds.  |
|  | Characteristics:  |
|  | <ul> <li>Sponsor supports research activities of an individual researcher or group of researchers. Sponsor does<br/>not restrict use of funds</li> </ul>  |
|  | Funds are paid in advance   |
|  | No invoicing or financial statements are required by Sponsor  |
|  | University/Host Institution retains all rights to inventions and other intellectual property  |
|  | University/Host Institution is free to publish results  |
|  | University/Host Institution provides the Sponsor with a final report only   |
|  | Parties to the Agreement: University/Host Institution and Sponsor (may include University/Host Institution Affiliated Hospitals)  |
| Other Funding Type: Service<br>Contracts<br>Added as sub-type of Other<br>Funding Type -ategory in FY<br>2010-11 | Characteristics: (1) Solely for testing, evaluation or analysis of materials or compounds owned by the Sponsor with no intellectual input or value-added by UBC. (2) Sponsor retains all rights to intellectual property provided by the Sponsor for the services   |
| Combined into one "Other"  |   |
| category as of FY 14-15  |   |

|  | GLOSSARY  |  |  |
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| Term   | Description [data source]   |  |  |
| Other Funding Type: Donations & Endowment Interest   | A donation is a gift given by an individual or an organization to a non-profit organization, charity or private foundation in support of a specific purpose.  |  |  |
| Added as sub-type of Other<br>Funding Type category in FY<br>2010–11                             | Endowment—gift of money or income producing property to a public organization (such as a hospital foundation or university) for a specific purpose (such as research or scholarships). Generally, the endowed asset is kept intact and only the income (known as endowment interest) generated by it is consumed. |  |  |
| Combined into one "Other" category as of FY 14-15  |   |  |  |
| Other Funding Type<br>Combined into one "Other"<br>category as of FY 14-15                       | Dollar amount for FY, combined, of any grant, award or contract that does not fit into the above categories. Please specify name of Funding Type in space provided.   |  |  |
| Funding Source Categories  | (rows)  |  |  |
| UBC RISe Sector  | Sector denotes an area of the <b>economy</b> in which the funder is assigned. This decision is based on how the organization is funded. Three sectors are currently utilized by UBC's Research Information System (RISe) and include:   |  |  |
|  | Non-Profit: funding provided mostly by private donations and endowments.  |  |  |
|  | Industry: funding provided by a for-profit business in the private or commercial sectors of business.   |  |  |
|  | <b>Government:</b> funding provided by local, provincial, national, federal or foreign government entity. [definitions to be further developed with input from Working Group and RISe personnel]  |  |  |
| Funding Sources/Granting Agency  | The rows on worksheet 1ab, 2b that correspond to the funding sources agreed to by the Research Metrics Working Group on July 22, 2009 and modified in subsequent fiscal years.  |  |  |
| CIHR and its institutes  | The Canadian Institutes of Health Research and its thirteen subsidiary institutes:  |  |  |
| (included in Major Canadian  | Aboriginal Peoples' Health  |  |  |
| Funding Category)  | · Aging   |  |  |
|  | · Cancer Research   |  |  |
|  | Circulatory and Respiratory Health  |  |  |
|  | · Gender and Health   |  |  |
|  | · Genetics  |  |  |
|  | Health Services and Policy Research   |  |  |
|  | Human Development, Child and Youth Health   |  |  |
|  | Infection and Immunity  |  |  |
|  | Musculoskeletal Health and Arthritis  |  |  |
|  | Neurosciences, Mental Health and Addiction  |  |  |
|  | Nutrition, Metabolism and Diabetes  |  |  |
|  | Population and Public Health  |  |  |
| CCSRI<br>(formerly NCIC/Canadian<br>Cancer Society/CCSR)   | On February 1 2009, the Canadian Cancer Society integrated the operations of the National Cancer Institute of Canada (NCIC), creating the Canadian Cancer Society Research Institute. Grants from all three of these organizations should go in this category.  |  |  |
| (name changed to CCSRI<br>for FY 11–12 and moved<br>to CDN Foundation & Non-<br>profit category) |   |  |  |

| GLOSSARY  |  |  |
|---|--|--|
| Term  | Description [data source]  |  |
| NSERC<br>(included in Major Canadian<br>Funding Category)   | Natural Sciences and Engineering Research Council  |  |
| SSHRC<br>(included in Major Canadian<br>Funding Category)   | Social Sciences and Humanities Research Council  |  |
| Genome Canada and<br>provincial Genome agencies<br>(included in Major Canadian<br>Funding Category)                         | Genome Canada, and its regional centres: Genome BC, Genome Alberta, Ontario Genomics Institute, Genome Quebec, Genome Prairie, and Genome Atlantic   |  |
| MSFHR<br>(included in Major Canadian<br>Funding Category)   | Michael Smith Foundation for Health Research (BC)  |  |
| Canadian Industry   | Canadian-based for-profit corporations. Decisions on whether a funding source is Canadian or Foreign are driven by award payment or contract address.  |  |
| Canadian Foundations & Non-Profits (name modified in FY 12–13 to align with UBC categories—all historical data was recoded) | Canadian not for profit organizations including foundations and charities. These include grants that are "internally" sourced (i.e. that are from BCCHR, BCCA or their affiliated Foundations such as BCWF, BCCHF, and BCCF etc.)      |  |
| Canadian Educational<br>Institution   | This was added in FY 09-10 as a separate Funding Source Category and includes all educational and/or academic institutions in Canada. Foreign Educational Institutions are categorized under Foreign Other Source.                     |  |
| Canadian Government   | Provincial, municipal, territorial or federal governments and crown corporations in Canada   |  |
| Foreign Industry  | For-profit corporations outside Canada. Decisions on whether a funding source is Canadian or Foreign are driven by award payment or contract address.  |  |
| Foreign Foundations & Non-Profits (name modified in FY 12–13 to align with UBC categories—all historical data was recoded)  | Not for profit organizations including foundations and charities headquartered outside Canada, e.g. March of Dimes, American Cancer Society  |  |
| Foreign Government  | Provincial, municipal, territorial or federal governments and government controlled corporations outside Canada including the armed forces (e.g. US Military)  |  |
| Foreign Other Source  | All Foreign funding sources not captured in the above Foreign categories including Foreign Educational Institutions.   |  |
|   | Types  under, sponsor, grantor, or agency (government, industry, and non-profit) that is providing the funds needed ects are not considered "For-Profit" if a sponsor is only collaborating and not funding the study (e.g., providing |  |
| Grant   | Funding provided for specific projects by sponsors in the government or non-profit sectors.  |  |
| For-Profit Sponsor (Industry or Pharmaceutical)   | Funding provided for specific projects by sponsors in the industry sector.   |  |

| GLOSSARY  |  |  |
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| Term  | Description [data source]  |  |
| Grant-in-aid  | Funding provided for general research activities by sponsors in any sector (Industry, Government or Non-profit)  |  |
| Internal Funding  | Funded by internal agency department, agency operational budget or non-profit foundation (e.g. salary award)   |  |
| No Funding  | No funding provided.   |  |
| Other   | Funding not yet known when ethics application was submitted.   |  |
| Multiple Funding Type   | Any combination of the above funding types.  |  |
| Research Trainees Categor   | ies (columns)  |  |
| Research Trainee  | Total number of research trainees by student type excluding clinical trainees who are supported during their brief research rotations. Research trainees counted will be any individuals who are primarily supervised by a researcher affiliated with the reporting unit, during all or a portion of the reporting year.   |  |
| Masters   | Graduate students enrolled in a full time Master's program who are supervised by a faculty member affiliated with the reporting organization.  |  |
| Doctoral (changed from PhD in FY 2010–11)   | Graduate students enrolled in a full time PhD program who are supervised by a faculty member affiliated with the reporting organization.   |  |
| Post-doctoral   | Full time post-doctoral fellows whose primary focus is research (NOT clinical fellows)   |  |
| Summer students (short term)  | High school and or university students who are engaged in a short term program with the reporting agency for a limited period (e.g. over the summer, a few weeks)  |  |
| Residents   | MDs engaged in a residency program that may include a research rotation  |  |
| Practicum, co-op, honors and directed studies students  | High school and/or university students whose assignment to the reporting organization is according to a practicum, co-op, honours and/or directed studies program  |  |
| Other Research Trainee<br>Type  | (Reporting organization to specify definition)   |  |
| Research Trainees (rows)  |  |  |
| Do you Support These<br>Types of Research Trainees  | To be answered Yes or No for each Research Trainee Category listed above. Is used to indicate that a research entity does have Research Trainees of this type but has no data collection ability. This will distinguish between those with zero (0) Trainee types from those that have them but can't count them.  |  |
| Total Head Count  | Total number of research trainees of that type, not an FTE (Full Time Equivalent number).  |  |
| List of Researcher Name (co   | olumns and row)  |  |
| Category  | A number one through five (MUST have one selected).  |  |
| (modified to add Shared<br>Membership sub-category<br>under BCCHR categories<br>1–3 in FY 2010–11)<br>Membership categories<br>revised FY 16–17 | Categories 1–4 are as described in the BCCHR "Guide for Completing an Application for Membership" available online at http://www.cfri.ca/research_support/forms/membership.asp. These categories are based on a calculation of a given individual's research hours/week.   |  |
|   | Category 5 will be for those research entities/agencies who do not utilize the CFRI categories. If you utilize category 5, please indicate the definition that your research entity/agency uses to define Researchers.   |  |
|   | A shared membership sub-category available in CFRI Categories 1–3 was added in FY 2010–11. This new category allows individuals to formally declare their alignments (including percentage affiliation) with more than one organization. Category 4 was clarified to include only affiliate investigators that are not based on site but who collaborate with agency members. Their primary affiliation will be with another academic and/or research institution. |  |
|   | New categories for FY 16-17: http://bcchr.ca/research-support/membership   |  |

| GLOSSARY   |  |  |
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| Term   | Description [data source]  |  |
| First, Last, Middle name                             | Self-explanatory, e.g. Jane Mary Smith   |  |
| Short Name   | Name as it would appear in PubMed, for example, Smith, JM  |  |
| Count Attributed to Agency Added in FY 11–12         | An indication by number (1 or .5) of whether a researcher is attributable to applicable agency 100% (full) or 50% (shared).  |  |
| UBC's definition of<br>Research<br>Added in FY 13-14 | UBC defines research involving human subjects as "any systematic investigation (including pilot studies, exploratory studies, and course based assignments) to establish facts, principles or generalizable knowledge which involves: living human subjects; or human remains, cadavers, tissues, biological fluids, embryos or foetuses." It does not include"quality assurance studies, performance reviews or testing within normal educational requirements, or activities undertaken for administrative or operational reasons" unless they include an 'element of research.' |  |
| Other  |  |  |
| Fiscal Year  | Includes data for April 1–March 31 of applicable fiscal year (i.e., FY 14–15 is April 1, 2014–March 31, 2015)  |  |