



CANADIAN INSTITUTES OF HEALTH RESEARCH'S SUBMISSION TO THE HOUSE OF COMMONS STANDING COMMITTEE ON HEALTH (HESA)

Motion M-132 on using federally funded research to improve access to medicines October 22, 2018

The Government primarily supports extramural health research through the Canadian Institutes of Health Research (CIHR). With an annual budget of approximately one billion dollars, CIHR provides leadership and support to health researchers and trainees across Canada throughout their careers. With a mandate to translate research evidence into improved health for Canadians, more effective health services and products and a strengthened Canadian health care system, CIHR has measures in place to ensure that the research it funds benefits Canadians. For instance, CIHR along with the two other federal research granting agencies (Natural Science and Engineering Research Council (NSERC) and the Social Sciences and Humanities Research Council (SSHRC)) have several policies in place to promote the accessibility of research data and results stemming from public funds. Further, as this brief will also highlight, CIHR supports the translation of research evidence into effective outcomes for Canadians through a number of its strategic initiatives.

Promoting health innovation through institutional policies

Momentum for open access has been growing as numerous funding agencies and institutions worldwide implement open access policies. CIHR strongly supports open **access to research results** which promotes the principle of knowledge sharing and mobilization – an essential objective of academia. Open access to research results helps to advance knowledge, avoid research duplication and encourage reuse, maximize research benefits to Canadians and showcase the accomplishments of Canadian researchers. Under the *Tri-Agency Open Access Policy on Publications*, researchers must ensure that peer-reviewed journal publications arising from CIHR-supported research are freely available within 12 months of publication by depositing manuscripts in an institutional or disciplinary repository and/or publishing in an open access journal. This allows the public to access findings, knowledge users to apply findings, and other researchers to build on the findings, thereby accelerating the translation of new knowledge into health innovations such as new drug therapies. CIHR encourages all researchers, regardless of funding support, to adhere to this policy.

CIHR also believes that **research data** collected with the use of public funds belong, to the fullest extent possible, in the public domain and available for reuse by others. When properly managed and responsibly shared, digital research data enables researchers to ask new questions, pursue novel research programs, and test alternative hypotheses. Building on the *Tri-Agency Statement of Principles on Digital Data Management*, released in 2016, the draft *Tri-Agency Research Data Management Policy* was released

for public consultation in the summer of 2018. The policy promotes sound data management and data stewardship practices. It would require CIHR grant recipients to deposit into a recognized digital repository all digital research data, metadata and code that directly support the research conclusions in journal publications, pre-prints, and other research outputs that arise from agency-supported research. It would further encourage researchers to provide access to the data where ethical, legal, and commercial requirements allow, and in accordance with the standards of their disciplines. In doing so, it has the potential to advance science and support innovative solutions in Canada, including the production of novel drug therapies. Consultations closed on August 31, 2018 and the final policy is forthcoming.

In addition, in accordance with the *Tri-Council Policy on Intellectual Property (IP)*, CIHR does not retain, or claim any ownership of, or exploitation or proprietary rights to, intellectual property, copyright or inventions developed/resulting from research supported with agency grant funds nor does it pass judgment on the eventual commercial success of the research. Intellectual property rights stemming from all CIHR-funded research is administered and owned by the host institutions, namely universities, which typically fall under provincial jurisdiction. Any global access licensing to this intellectual property remains at the discretion of the owner. While CIHR does not retain ownership of IP, we encourage funded researchers to engage in knowledge translation (KT) as it is an important process that bridges the gap between research and practice and ensures a meaningful use of the data.

Promoting health innovation through strategic programming

Through its research investments, CIHR continues to generate new knowledge and evidence that leads to better and more affordable treatments for Canadians. For example, one of CIHR's major initiatives is Canada's Strategy for Patient-Oriented Research (SPOR), which is a unique collaboration of federal, provincial and territorial partners, all dedicated to the integration of research evidence into care. As part of SPOR, CIHR is investing \$11.7 million a year in the innovative Clinical Trials (iCT) Initiative that focuses on the development and implementation of innovative methods in clinical research. The iCT Initiative will provide a stimulus for researchers to adopt new methodologies to conduct clinical trials. These new methods can reduce the cost of conducting trials, reduce the amount of time needed to answer research questions, and increase the relevance of research findings to patients, health care providers and policy makers.

The direct outcome of these new methods is an improved effectiveness of clinical trials while keeping the same high safety and effectiveness standards as traditional trials. Specifically for drug trials, this approach may potentially contribute to lowering the cost of drug development, ensuring that new affordable and effective drugs are available for Canadians.

Further, CIHR supports SPOR Networks which are national collaborative research networks involving researchers, patients, policy makers, academic health centres,

health charities, and other stakeholders. SPOR Networks focus on specific health areas identified as priorities in multiple provinces and territories. The Networks address research priorities identified by patients and accelerate the translation of research findings into patient care and health care policy, including priorities related to the development of new therapies and improved access to medications.

Through international collaborations, CIHR also supports the translation of research evidence into health innovations that have the potential to make a real impact on the health of Canadians, particularly those living with rare diseases. For example, Canada, through CIHR, is a founding member of the International Rare Diseases Research Consortium (IRDiRC), which aimed to deliver 200 new therapies for rare diseases by 2020. As of 2016, IRDiRC has bi-passed this goal and a new goal of delivering 1000 new therapies has been set for the next 10 years. Canada is also engaged in E-Rare, the European Union's main instrument for funding research in areas related to rare diseases. This initiative enables scientists in different countries to collaborate on a common interdisciplinary research project, with a clear translational approach.

In addition, in 2009 CIHR and Health Canada (HC) created the Drug Safety and Effectiveness Network (DSEN) to systematically conduct "real world" drug safety and effectiveness research required by Canadian decision-makers. DSEN is a national network of over 150 researchers and receives \$10 million per year in ongoing funding from the Government of Canada to support its activities. To facilitate the knowledge translation process, DSEN developed a collaborative agreement with the Canadian Agency for Drugs and Technologies in Health (CADTH), an independent organization, to disseminate DSEN study results to provincial and territorial health authorities. DSEN is another example of an initiative, supported by CIHR and HC, which creates the capacity to respond in a timely manner to the drug safety and effectiveness queries of decision makers, and ensures that the most effective drugs are accessible to Canadians.

A further example of CIHR programming that supports health innovation is the Best Brain Exchanges (BBE) program which is designed to deliver high-quality, timely, and accessible research evidence that responds to health system policy issues and gaps in knowledge, to inform policy development, planning and program implementation. For example, in 2016, CIHR, in collaboration with the Ontario Ministry of Health and Long-Term Care, hosted a BBE that explored leading research and implementation evidence to support the collaborative efforts of the Federal, Provincial and Territorial governments in relation to the accessibility, appropriateness, and affordability of prescription drugs. In 2016, CIHR, in collaboration with HC and the Canadian Centre on Substance Abuse (CCSA), also hosted a BBE that brought together Canadian and international policy and decision makers, researchers and key stakeholders (including drug surveillance, substance abuse, and public health and public safety experts) to discuss how best to collect data to inform drug policy decisions and to monitor their impacts.

Additionally, CIHR, in collaboration with NSERC and SSHRC, supports the Networks of Centres of Excellence (NCE) initiative that mobilizes Canada's best research,

development and entrepreneurial expertise and focuses it on specific issues and strategic areas, including the area of pharmaceutical development. For example, CQDM (formerly known as the Consortium québécois sur la découverte du médicament), an NCE, has developed proven investment models that are reducing risk through open innovation and collaborative R&D with pharmaceutical companies, early-stage biotech companies, academia and public bodies to accelerate the development and validation of precompetitive research tools and platforms for the development of safer and more effective drugs. The NEOMED Institute, another NCE, focuses on identifying promising drug discovery projects emerging from academia and small-and medium-sized enterprises (SMEs) and works closely with project originators, academic laboratories and contract research organizations to advance the research to the all-important proof-of-concept stage in humans. This approach creates strong ties between SMEs and international pharmaceutical companies, and new opportunities to conduct clinical trials of new drugs in Canada. A further example is Accel-RX Health Sciences Accelerator (Accel-RX), an NCE that leverages the expertise and infrastructure of seven health-related Centres of Excellence for Commercialization and Research (CECRs), including the Centre for Drug Research and Development (CDRD), to aid in the further screening and evaluation of technologies with the highest technical and commercial potential. Accel-RX, in partnership with MaRS Innovation and CDRD, invested \$525,000 in Zucara Therapeutics to develop an antibody treatment for insulin dependent diabetics to prevent hypoglycemia. This investment will allow Zucara to select a lead candidate and generate in vivo validating data to support a clinical trial application. Accel-Rx, in partnership with the Business Development Bank of Canada, has also previously led a number of drug related investments including: \$2.85 million in Encycle Therapeutics for proprietary macrocycle synthesis platform technology, \$2 million in ScarX Therapeutics for an anti-scarring topical cream and \$1.8 million in ImStar Therapeutics for a novel drug treatment for ALS.

Through institutional policies, CIHR ensures that federally-funded research makes good use of public funds, experiments and studies are replicable, and research results are as accessible as possible. Through its strategic programming, CIHR supports new scientific knowledge and enables its translation into improved health services and products and more effective health outcomes for Canadians. Together, these concrete actions ensure that Canadians have better access to the science supported by the federal government.

Should you require further information please do not hesitate to contact me.


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