

CGP ANNUAL REPORT

2019

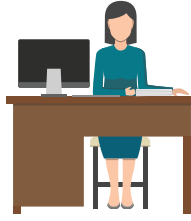


CGP
THE LAST

10
YEARS

McGILL UNIVERSITY

120
YOUNG
RESEARCHERS



175
RESEARCH
PROJECTS



690
PUBLICATIONS



2 NEW COURSES
GIVEN TO MORE THAN
200 STUDENTS



RESEARCH AWARDS

**Canada Research Chair in Law and
Medicine** (Prof. Bartha Knoppers)



FRQS Chercheurs boursiers Junior 1 & 2
(Prof. Yann Joly)



Bartha Knoppers, Director
Yann Joly, Research Director
Ma'n Zawati, Executive Director
Gratien Dalpé, Coordinator

Denise Avard, Past Research Director
Nicole Palmour, Past Executive Director
Claude LaBerge, Scientific Advisor

CGP 10 YEARS

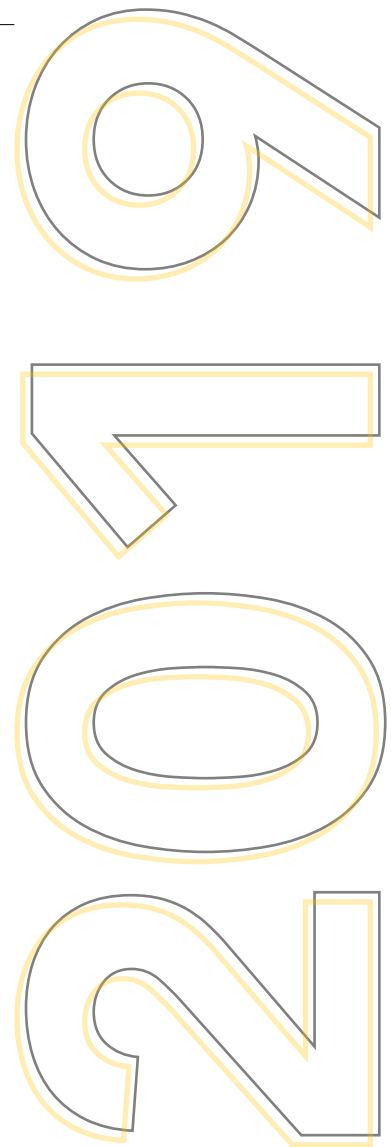


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CGP

DIRECTOR

As is evident from the photo on both the inside front and back covers of our 2019 Annual Report, we had much to celebrate on the anniversary of our 10th year at McGill University on June 19th!

The figures speak for themselves (*res ipsa loquitur*).

Who cannot be proud of such a vibrant and productive team? What makes our research distinct? It is:

- comparative in nature
- provides international policy analysis
- is interdisciplinary and innovative, and,
- builds tools and policy frameworks, while crossing all – omics.

This year also marks a foray into even more international collaborations and into new domains such as genome editing, neuroscience, pathogens, artificial intelligence, and the Human Cell Atlas – all incredibly challenging (and fun).

May 2020 bring us the time, energy and funding to meet these new challenges while anticipating new ones.



Prof. Bartha Maria Knoppers

CONGRATULATIONS, DR. BARTHA MARIA KNOPPERS!

The Henry G.
Friesen
International Prize
in Health Research



"Friends of CIHR is pleased to announce that Dr. Bartha Knoppers, a global leader in the study of legal, social and ethical issues related to biomedical research in human genetics and genomics, was awarded the 2019 Henry G. Friesen International Prize in Health Research.

Toronto – March 18, 2019 – Dr. Bartha Knoppers, PhD, ADE, OC, OQ, FRSC, FCAHS, is one of the most prolific and innovative health policy researchers in Canada and beyond. She has been a leader in the interface of ethics and law, as applied to health research policy, stem cell research, human gene editing, biobanking and global data sharing. Bartha is also a brilliant science communicator and public figure, who gives generously of her time for social good.

The Henry G. Friesen International Prize in Health Research was established in 2005 by Friends of CIHR in recognition of Dr. Friesen's distinguished leadership, vision and innovative contributions to health research and health research policy.

The award, announced each spring, supports an annual fall lecture or series of lectures by a worthy and accomplished speaker of international stature on topics related to the advancement of health research and its evolving contributions to society. The Lecture endeavours to reach the broadest possible audience at major centres across Canada. Additional institutional visits ensure national impact."



CGP

RESEARCH DIRECTOR

Dear readers,

2019 saw the CGP consolidate its position as one of the lead research centres in the world on the ethical, legal and social issues related to genetics and multi-omics. The 54 articles published by members of the CGP in 2019, and the significant research contributions we have made on topical issues associated with epigenetics, gene editing through the CRISPR/Cas9 system, mobile health applications, pathogen data sharing and food safety, and data sharing in research and clinical settings all contributed to this achievement. We have also actively contributed to the success of organizations such as the Global Alliance for Genomics and Health, the Human Cell Atlas, as well as the Observatory on the Societal Impacts of Artificial Intelligence.

Professor B.M. Knoppers organized a think tank held in Montreal and co-signed an article published in *Science* on advances in biomedical sciences that blur the classical legal boundaries that form the basis of the normative structures on which our societies are built. I remained busy preparing the international launch of the Genetic Discrimination Observatory (GDO) (<https://gdo.global/en>), which now includes experts from 16 countries. The launch will be made official in *Nature Genetics* in early 2020. Furthermore, I am proud to highlight the promotion of my dear colleague and Executive Director of the CGP, Dr. Ma'n Zawati, as Assistant Professor at the Faculty of Medicine!

Finally, I am also pleased that we were able to secure funding for 12 new research projects this year and that we had the opportunity to welcome 7 invited scholars, 4 graduate students, 4 articling students and 9 interns. We look forward to collaborating with our research colleagues in future national and international funding opportunities in 2020, where our team will continue to propose innovative projects with varied, multidisciplinary and cutting-edge methodologies to help bring scientific advances and research to the clinic.

Prof. Yann Toly

CGP

ABOUT US

Located within the McGill Genome Centre, the Centre of Genomics and Policy (CGP) works at the crossroads of law, medicine, and public policy. Applying a multidisciplinary perspective and collaborating with national and international partners, the CGP analyzes the socio-ethical and legal norms influencing the promotion, prevention and protection of human health.



PHOTO BY Scott Norsworthy

Currently, the CGP's research covers several areas of genomics and policy including: genetic discrimination, stem cell therapy, intellectual property and open science, biobanking, personalized medicine, pediatrics (gene therapies), rare diseases, epigenomics, prevention and treatment of cancer, data sharing in research, mobile health, intersex studies, genetic counseling, agrogenomics and food safety, gene editing and genetic enhancement.

These domains are approached using three guiding foundations: internationalization, policy development and knowledge transfer. First, the CGP promotes internationalization by undertaking comparative analyses of policies and guidelines around the world. Secondly, the CGP actively participates in the creation of international consortia with a view to promoting multidisciplinary policymaking. Finally, via its numerous workshops and lecture series, the CGP encourages knowledge transfer.

PROFESSOR

KNOPPERS Bartha Maria - DIRECTOR

ASSOCIATE PROFESSOR

JOLY Yann - RESEARCH DIRECTOR

ASSISTANT PROFESSOR

ZAWATI Ma'n - EXECUTIVE DIRECTOR

ACADEMIC ASSOCIATES

DALPÉ Gratien - COORDINATOR

GRANADOS-MORENO Palmira

HAGAN Julie

KLEIDERMAN Erika

LANG Michael

LÉVESQUE Emmanuelle

NGUENG FEZE Ida

NGUYEN Minh Thu

PHILLIPS Mark

SAULNIER Katie

SÉNÉCAL Karine

SONG Lingqiao

TASSÉ Anne-Marie

THOROGOOD Adrian

ASSOCIATE MEMBERS

BEREZA Eugene

GOLD Richard

KIMMELMAN Jonathan

SCIENTIFIC CONSULTANTS

AVARD Denise

LABERGE Claude

POST DOCTORAL FELLOW

DUPRAS Charles

INVITED SCHOLARS

ISASI Rosario

ISSA Amalia

KIM Hannah

MURTAGH Madeleine

ROSKAMS-EDRIS Dylan

SUNU Kyungyun

WALLACE Susan

RESEARCH ASSISTANTS

ALARIE Samuel

BEAUCHAMP Elisabeth

BEAUVAIS Michael

BERNIER Alexander

CARON Roxanne

CAULFIELD Alison

CHANG Mei-Chen

GALLOIS Hortense

GRAHAM Leah

HARVEY-CHEETHAM Anthea

KÉKESI-LAFRANCE Kristina

KNOPPERS Teres

KRABCHI Hanna

LAGUIA Kristen

LANGLOIS Vincent

LIU Hanshi

OLVERA Elena

PATRINOS Dimitri

PINKESZ Miriam

TOURÉ Seydina

XU Handi

MASTER'S STUDENT

CROCKER Kelsey

Ph.D. STUDENTS

NOOHI Forough

RAHIMZADEH Vasiliki

SO Derek

INTERNS

ANASTASIO Natascia

BACKMAN Samantha

DIAS Julie-Alexia

OLIVIERO Elisabeth

SCHMILOVICH Zoe

SCHNEIDER Oliver

VACCARELLA Amanda

WARMAN Jodi

YAO Karen

ADMINISTRATORS

HOZYAN Rose-Marie

THORSEN Nadine

CGP TEAM

2019





BARTHA M. KNOPPERS
DIRECTOR

Bartha Maria Knoppers, PhD (Comparative Medical Law), is a Full Professor, Canada Research Chair in Law and Medicine and, Director of the Centre of Genomics and Policy of the Faculty of Medicine at McGill University. She was the Chair of the Ethics and Governance Committee of the International Cancer Genome Consortium (2009-2017). She is currently Chair of the Ethics Advisory Panel of WADA (2015), and from 2013 onward, is Co-Chair of the Regulatory and Ethics Workstream of the Global Alliance for Genomics and Health. In 2015-2016, she was a member of the Drafting Group for the Recommendation of the OECD Council on Health Data Governance and gave the Galton Lecture in November 2017. She holds four Doctorates Honoris Causa and is a Fellow of the American Association for the Advancement of Science (AAAS), the Hastings Center (bioethics), the Canadian Academy Health Sciences (CAHS), and, the Royal Society of Canada. She is also an Officer of the Order of Canada and of Quebec, and, was awarded the 2019 Henry G. Friesen International Prize in Health Research and, was appointed to the International Commission on the Clinical Use of Human Germline Genome Editing.



YANN JOLY
RESEARCH DIRECTOR

Yann Joly, Ph.D. (DCL), FCAHS, Ad.E. is the Research Director of the Centre of Genomics and Policy (CGP). He is an Associate Professor at the Faculty of Medicine, Department of Human Genetics cross-appointed at the Bioethics Unit, at McGill University. He was named advocatus emeritus by the Quebec Bar in 2012 and Fellow of the Canadian Academy of Health Sciences in 2017.

Prof. Joly is a member of the Canadian Commission for UNESCO (CCU) Sectoral Commission for Natural, Social and Human Sciences. He is the current Chair of the Bioethics Workgroup of the International Human Epigenome Consortium (IHEC) and Co-Lead of the regulatory and ethics work stream of the Global Alliance for Genomics and Health (GA4GH). He was Chair (2017-2019) of the Ethics and Governance Committee of the International Cancer Genome Consortium (ICGC). He is also a member of the Human Genome Organization (HUGO) Committee on Ethics, Law and Society (CELS).

Prof. Joly's research interests lie at the interface of the fields of scientific knowledge, health law (biotechnology and other emerging health technologies) and bioethics. He created the first international genetic discrimination observatory (GDO; <https://gdo.global/en/gdo-description>) in 2018. He has published his findings in over 150 peer-reviewed articles featured in top legal, ethical and scientific journals. He served as a legal advisor on multiple research ethics committees in the public and private sectors. Prof. Joly also sits on editorial committees and acts as a reviewer for a wide range of publications in his field. In 2012, he received the Quebec Bar Award of Merit (Innovation) for his work on the right to privacy in the biomedical field.



MA'N H. ZAWATI
EXECUTIVE DIRECTOR

Ma'n H. Zawati (LL.B., LL.M., Ph.D. (DCL)) is an Assistant Professor at McGill University's Faculty of Medicine and the Executive Director of the Centre of Genomics and Policy in the Department of Human Genetics. He is also an Associate Member of McGill's Biomedical Ethics Unit. His research concentrates on the legal, ethical and policy dimensions of health research and clinical care, with a special focus on biobanking, data sharing, professional liability, and the use of novel technologies (e.g. mhealth apps, WGS, WES) in both the clinical and research settings. Dr. Zawati is funded by Genome Canada, Genome Quebec and the Terry Fox Research Institute. His work is interdisciplinary, drawing together perspectives from law, ethics, bioinformatics, genomics, and policy. He's also a frequent presenter on a variety of the most critical and topical issues in healthcare and the biosciences. He has appeared at 100+ international conferences, symposia, meetings, and has shared his expertise with universities, research ethics boards and law firms. Dr. Zawati has published 13 book chapters and 45+ peer reviewed articles in leading publications such as Nature Reviews Genetics, the Canadian Medical Association Journal, the Journal of Law and the Biosciences, the Journal of Medical Genetics, and the McGill Journal of Law and Health. In 2015, he was awarded the Queen Elizabeth II Diamond Jubilee Scholarship (stay at Oxford University) and was named a Royal Society of Canada Delegate for the IAP Young Scientists of the Year international symposium. In 2014, the Young Bar Association of Montreal named him as one of its Lawyers of the Year.



GRATIEN DALPÉ
COORDINATOR
ACADEMIC ASSOCIATE

Gratien Dalpé completed his undergraduate and master studies (B.Sc./M.Sc) in biochemistry at the University of Sherbrooke. He holds a doctorate degree (Ph.D.) in molecular biology from the University of Montreal. He later worked as a post-doctoral fellow and research associate at the Samuel Lunenfeld Research Institute in Toronto. During his career, he uncovered new molecular signalling networks regulating the development and degeneration of the nervous system. With an interest in law and bioethics, he later obtained his LL.B. in civil law at the University of Montreal and joined the Centre of Genomics and Policy as an academic associate. He is also the Coordinator of the Centre of Genomics and Policy.



PALMIRA GRANADOS M.
ACADEMIC ASSOCIATE

Palmira Granados-Moreno (LL.M., Ph.D) is a Mexican lawyer and Academic Associate specialized in the intersection of intellectual property and life sciences and bioethics. She recently obtained her doctorate from the Faculty of Law at McGill University under the supervision of Professor Richard Gold. She has published and presented her work in international fora on intellectual property and biomedicine; intellectual property and information technologies; commercialization; genetic discrimination and immigration; legal issues associated with open science in biomedicine; and bioethics. She is a guest lecturer in the graduate classes of Genetics and Bioethics at McGill University and Global Health Ethics at the University of Southern California, San Diego. She is a member of the International Expert Group of the Genetic Discrimination Observatory and the Centre for Intellectual Property and Policy of McGill University.

She obtained her law degree from la Escuela Libre de Derecho in Mexico and her LL.M from the Faculty of Law at the University of Toronto.



JULIE HAGAN
ACADEMIC ASSOCIATE

Julie Hagan (B.Sc./M.Sc) is an Academic Associate at the Centre of Genomics and Policy (CGP) at McGill University. She obtained a Master's degree in sociology from Université de Montréal and completed a doctoral internship at the University of São Paulo, Brazil. She is pursuing a Ph.D. in sociology at Laval University. At the CGP, she contributes her experience in qualitative research methodologies to foster stakeholders engagement. She is currently involved in research about the social acceptability of omics approaches for the detection of Salmonella in fresh produces. She is also involved in projects examining how the changes brought about by the advances in genomics and the development of personalized medicine affects patients and health professionals as well as its effects on service delivery and policymaking.



EMILY KIRBY
ACADEMIC ASSOCIATE

Emily is a lawyer and Academic Associate at the Centre of Genomics and Policy (CGP), McGill University. She holds degrees in biology (B.Sc. McGill University), a Master's in Environmental Project Management (M. Env., Université de Sherbrooke), and a Civil Law degree (LL. B., Université de Montréal). She has been a member of the Québec Bar since 2011. Prior to joining the CGP, Emily was a project coordinator at the Public Population Project in Genomics and Society (P3G). She currently works on the development of ethical and legal documents and tools used to facilitate policy interoperability and data sharing in the context of data-intensive research (-omics, clinical data, etc.). Emily has been involved in examining ethical, legal and policy issues in a number of Canadian and international data sharing initiatives (e.g. MSSNG database, Care4Rare-SOLVE, Terry-Fox PROFYLE, International Cancer Genome Consortium (ICGC) for medicine, Human Cell Atlas, Global Alliance for Genomics and Health task forces, Transforming Autism Care Consortium's Q1K project, etc.). She is currently the Academic Coordinator of the Ethics Working Group of the Human Cell Atlas (HCA; <https://www.humancellatlas.org/>).

CGP TEAM



ERIKA KLEIDERMAN
ACADEMIC ASSOCIATE

Erika is a lawyer and an Academic Associate at the Centre of Genomics and Policy (CGP) at McGill University. She holds a civil law degree (LL.B.) from the Université de Montréal, as well as a B.Sc. in Psychology from McGill University. She was called to the Quebec Bar in 2014.

Her research focuses on the ethical, legal, and social implications surrounding human genome editing, new assisted reproductive technologies, stem cell research, and cell and gene therapies, as well as access to data and genetic information (biobanking). Erika is also interested in implications of gene therapy and enhancement in minors within a sporting context. She is actively engaged in the stem cell and regenerative medicine community through her involvement with various committees, networks and initiatives. Erika is a member of CIHR's Stem Cell Oversight Committee and the McGill University Health Centre Research Ethics Board.



MICHAEL LANG
ACADEMIC ASSOCIATE

Michael is a member of the Law Society of Ontario and a graduate of McGill University's Faculty of Law (BCL/LLB, 2018) and of the University of Alberta (BA, 2014). During law school, he wrote an honours paper on the history of the tort of wrongful life, was executive editor of the McGill Journal of Sustainable Development Law, and was co-convenor of a student-initiated seminar on fertility law. His research focuses on the ways that technology is changing healthcare, with a particular focus on mobile health applications, artificial intelligence, and professional responsibility. Michael is broadly interested in the ways that technology affect the relationship between physicians and their patients, how the law understands personhood, and how humans interact with the natural environment.



EMMANUELLE LÉVESQUE
ACADEMIC ASSOCIATE

Emmanuelle is a lawyer and a member of the Québec Bar. She holds a Masters of law (specializing in biotechnology, law and society) from the University of Montreal and an LL.B. from Laval University. Her masters thesis is an analysis of the protections offered by the Canadian Charter and the Québec Charter against genetic discrimination in the workplace.

Emmanuelle works at the Centre of Genomics and Policy of McGill University. She specializes in questions concerning ethical and legal issues in health research, particularly in biomedical and genetic research. Over the past several years, she advises researchers about the ethical and legal issues raised by the deployment of their projects, especially about the development and the framework of biobanks. She works on projects conducted in Quebec, in the rest of Canada and overseas. She has published several publications and held conferences on different ethical and legal issues raised by research.



IDA NGUENG FEZE
ACADEMIC ASSOCIATE

Ida is a lawyer and member of the New York Bar. Her research projects at the CGP deal with the applications of novel biotechnologies in health and environmental contexts.

In terms of health applications, her work focuses on data governance and the ethical, legal and social implications of the collection, access and uses of human and pathogen genomic data. She has served as a member of the research ethics board of the Montreal General Hospital. In the environmental context, she has worked on several Genome Canada large-scale projects including the Salmonella Syst-OMICS (food safety and pathogen) and the Applied metagenomics of the Watershed (water quality).

She is a guest lecturer at the University of Montreal and Laval University teaching sessions on bioethics.

Before joining the Centre she worked at the UNFAO, the Environmental Law Institute and a law firm in the USA.



MINH THU NGUYEN
ACADEMIC ASSOCIATE

Minh Thu holds a Master of Laws (LL.M.) degree in Health Law and Policy from the University of Toronto, a Civil Law (LL.B.) degree from the Université de Montréal, and a B.Sc. degree in Physical Therapy from McGill University. She was a fellow of the Canadian Institute for Health Research - Health Law and Policy Program (2009) and coordinator of the P3G International Paediatric Research Programme (2012-2013). She has managed the ELSI Platform for the ThéCell Network and has been involved in several Canadian Stem Cell Network funded projects dealing with the regulation of cell and tissue therapies in Canada. She has worked on the development of model consent and information forms for rare disease research projects such as FORGE and CARE for RARE (pan-Canadian) and PRISMES (Quebec). Her work focuses on the socio-ethical and legal aspects of paediatric genetic research, rare disease research, cell/tissue therapy and regenerative medicine. She also has an interest in reproductive health law, particularly issues surrounding emerging reproductive technologies, such as prenatal diagnosis and pre-implantation genetic diagnosis.



MARK PHILLIPS
ACADEMIC ASSOCIATE

Mark Phillips works in comparative privacy and data protection law, particularly where it intersects with health data sharing. His academic background is in law and computer science, and he is a practicing member of the Quebec Bar Association. He works at the Centre of Genomics and Policy at McGill University as an Academic Associate, and is the co-chair of the Data Protection Task Team of the Global Alliance for Genomics and Health's Research and Ethics Work Stream. His comparative legal research focuses on topics including cloud computing, the identifiability of personal data, bioinformatics, and open data.



KATIE SAULNIER
ACADEMIC ASSOCIATE

Katie Saulnier graduated from Mount Allison University in 2010 with a Bachelor of Arts (Philosophy and English) focusing on ethics, and from the McGill Faculty of Law in May 2014 with a Bachelor of Civil Law (B.C.L.) and a Bachelor of Common Law (LL.B.). They were called to the Bar of the Law Society of Ontario in June 2016. They are currently pursuing an M.A. in philosophy with a specialization in bioethics from McGill University (2020), focusing on using a disability theory lens to examine the ways in which discourse around epigenetic research is changing conceptions of normative values assigned to bodies.

At the CGP, Katie is currently involved in research into the ethical, legal and social issues surrounding epigenetics and data sharing, as well as research on improving the quality of healthcare communication for intersex Canadians. Their other research interests include the ethical implications of depictions of reproduction and reproductive technologies in speculative fiction, issues with conceptions of autonomy in laws affecting women and Indigenous communities, and gender, neurodiversity and disability theory as they relate to the field of genomics.



KARINE SÉNÉCAL
ACADEMIC ASSOCIATE

Karine holds a Master's degree in Law (Biotechnologies and Society) from the Université de Montréal and a Bachelor of Laws from the Université du Québec à Montréal. Her master's thesis focused on the legitimacy of a restricted application of germline gene therapy, from a human rights perspective and research ethics. Her thesis was published by the editor Themis, in 2007. Karine is an Academic Associate at the Centre of Genomics and Policy at McGill University. She specializes in comparative law and policies, as well as in the analysis of the ethical, legal, and social implications surrounding genomic research and modern medicine. Her main areas of research are paediatric research, genetic testing and screening of minors as well as on the governance and ethics interoperability of paediatric biobanks and databases (including access, use and sharing). Karine is a coordinator of the Paediatric Task Team of the Global Alliance for Genomics Health, a consultant for the Policy Partnerships Project for Genomic Governance (P3G2), and an associate member of the Quebec Network of Applied Genetics (RMGA). She sits on committees for the assessment of issues raised by biomedical technologies or on public health questions. She is author and co-author of more than 40 publications, including books or book chapters, peer-reviewed articles and policies.

CGP TEAM



LINGQIAO SONG
ACADEMIC ASSOCIATE

Ms. Lingqiao Song acquired a B.Sc in Biology and Master Degree of Civil Law at the Chinese Academy of Social Science in China. In 2015, she completed her second master degree of international business law at University of Montreal and awarded "Dean's Award: Best Overall Academic Achievement". In 2016, she was admitted as Chinese Lawyer and working as a legal consultant for Anran Law firm China. She is also a member of Institutional Review Board of Faculty of Medicine, McGill University and assistant to the Data Access Officer of ICGC. At the Centre of Genomics and Policy, Lingqiao is working with Prof. Yann Joly and Ms Ida Ngueng Feze focusing on Ethical, Legal, Social Issues (ELSI) of gene technology, such as intellectual property law of biotechnology, misuse of genetic information outside of therapeutic context, policy approaches to address genetic discrimination, global data sharing of biobank and regulatory framework of microbiological genetic test.



ANNE-MARIE TASSÉ
ACADEMIC ASSOCIATE

Anne-Marie Tassé (LL.B., LL.M., M.A., LL.D.) is a lawyer specialised in health law and bioethics. She holds a Doctorate in Law (Université de Montréal), Master's degrees in Health Law (Université de Sherbrooke), and in Bioethics (Université de Montréal), and a Certificate in Health and Social Services Management (Université du Québec). Her work looks primarily at interactions between law and ethics, in the areas of international biomedical and genetic research.

Specialised in international comparative law, she is the Executive Director of P3G (Public Population Project in Genomics and Society) and an Academic Associate at the Center of Genomics and Policy (McGill University). As such, she coordinates the legal and ethical aspects of Canadian and international research projects. Author of more than 40 books, book chapters, peer-reviewed articles, policies and guidelines, her work is presented in Canada and abroad.



ADRIAN THOROGOOD
ACADEMIC ASSOCIATE

Adrian (B.A.&Sc., B.C.L.&LL.B., LL.M.) is a lawyer and Academic Associate at the Centre of Genomics and Policy. His legal research focuses on how genomic sequencing, cyberinfrastructure, open science practices, and patient empowerment movements are disrupting biomedical research and health care. He is also the Regulatory and Ethics Manager of the Global Alliance for Genomics and Health, a public-private consortium that develops standards to enable responsible genomic data exchange. In this position, he leads the development of international policy frameworks addressing consent, privacy and security, and coordinated research oversight. He also works with the neuroscience community in Canada to promote open science practices. Adrian completed his LL.M. at the University of Toronto. His thesis proposed strategies to overcome incompatibilities between legal systems that hinder international health research. Adrian holds a joint common law / civil law degree from McGill University.



CHARLES DUPRAS
POST-DOC FELLOW

Charles Dupras completed a PhD in bioethics at the University of Montreal, then was awarded a CIHR fellowship for pursuing his research on epigenetics. Charles is exploring laws and public policies potentially applicable to epigenetic research and technologies, such as DNA methylation tests. The main objective is to ensure that regulations, such as the Genetic Non-Discrimination Act (2017) and guidelines for the ethical conduct of genetic research (data sharing, privacy) apply justifiably to epigenetic information. Other ongoing projects include empirical studies of the ethical and social acceptability of non-invasive prenatal testing. Charles sits on the Executive Committee of the Canadian Journal of Bioethics, and the Scientific Counsel of the Institut national d'excellence en santé et services sociaux (INESSS) du Québec. He is also an active member of the Bioethics Workgroup of the International Human Epigenome Consortium (IHEC).

CGP STUDENTS



DEREK SO
PHD STUDENT

“The Role for Images of Human Genomic Engineering in Assessing Societal Views Relevant to Policy”

Supervisor: Yann Joly, Centre of Genomics and Policy, McGill University.
Co-Supervisor: Rob Sladek, Department of Human Genetics, McGill University.

Recent advances in gene editing technology have renewed a longstanding bioethical debate about making heritable genetic modifications in humans. For many decades, various communities have envisaged different scenarios for the intentional selection of human traits, producing a repository of images which continue to evoke strong moral responses and to shape popular, bioethical and literary discourses alike. Studying this body of thought can help us to develop policy on gene editing by learning more about the ways people tend to conceptualize the human genome, genetic disorders, and the act of genetic modification. The aim of this thesis is to provide a theory accounting for these schemata, in order to help clarify the socio-cultural influences on stakeholder values toward gene editing. To this end, reviews of both academic and popular discourse will be performed, as well as surveys aimed at eliciting the views of different stakeholders, and a discussion paper to disseminate the resulting framework.



VASILIKI RAHIMZADEH
PHD STUDENT

“Evaluating the Gap Between Research Ethics Review Governance and Data Sharing for Pediatric Genomics in Canada Genomic Medicine in International Health: The Role of International Open Science Genomic Projects”

Supervisor: Bartha Maria Knoppers, Centre of Genomics and Policy, McGill University.
Co-Supervisor: Gillian Bartlett, Department of Family Medicine, McGill University.

Biomedical research has increasingly become data-intensive and requires collaboration between researchers and research institutions, often across Canada and the world. Delivering on the innovative promises of precision medicine rests on the ability to share genomic and associated clinical data from patients, including from children. This is because large volumes of such data are needed to make sound scientific associations between the human genome and (childhood) disease. The sharing of genomic and associated clinical data involving children may, however, accentuate the need for special ethical-legal protections given their inability to consent alone to data sharing, and the longitudinal implications of their data contributions. To date, limited research attention has been paid to the ethical-legal challenges of sharing data from children, nor what impact it might have on researchers' ability to collaborate. This PhD thesis combines case study research and policy Delphi methods to explore the relationship between research ethics review policy and genomic data sharing for studies involving children across Canada.



FOROUGH NOOHI
PHD STUDENT

“Promoting Responsible Governance of Mitochondrial Replacement Therapy in Canada”

Supervisor: Yann Joly, Centre of Genomics and Policy, McGill University.

Mitochondrial Replacement Therapy (MRT) is a new type of in vitro fertilization that aims to prevent the transmission of mitochondrial diseases by replacing the mitochondria of unfertilized oocytes or zygotes with normal mitochondria from a healthy donor. Since mitochondria have their own DNA distinct from nuclear DNA, MRT is often referred to as “three-parent IVF”. Besides the UK, which became the first country to approve MRT in 2015, only a few countries have addressed this controversial technique through public policy. This PhD thesis aims to fill the important gaps in the MRT debate by using qualitative methods.



KELSEY CROCKER
MASTER'S STUDENT

“Investigating the Perceptions of Genetically Edited Individuals by Healthcare Providers to Inform Future Medical Practice and Policy”

Supervisor: Yann Joly, Centre of Genomics and Policy, McGill University.

Kelsey is a Master of Science student in the Department of Human Genetics at McGill University and Génome Québec Innovation Centre under the supervision of Dr. Yann Joly. She obtained a Bachelor of Science (High Distinction), majoring in both Fundamental Genetics and its Applications and Ecology and Evolutionary Biology at the University of Toronto in 2019. During her bachelor's, Kelsey completed a University Research Apprentice Program (URAPs) at the National University of Singapore in summer 2018. This research was focused on the Androgen-dependent tissue factor gene (ADTRP) and its association with coronary heart disease through the exploration of variable tandem repeats.

Kelsey's research at the Centre of Genomics and Policy focuses on the ethical implications of genetic discrimination.



ROSARIO ISASI | UNIVERSITY OF MIAMI

Rosario Isasi, J.D., M.P.H., is a Research Assistant Professor at the Miller School of Medicine with appointments in the Dr. J. T. Macdonald Foundation Department of Human Genetics, the Institute for Bioethics and Health Policy, the John P. Hussman Institute for Human Genomics, and the Interdisciplinary Stem Cell Institute. Her expertise is in the area of comparative law and ethics regarding genomics and regenerative medicine. Ethics Advisor to the European Commission's European Human Pluripotent Stem Cell Registry (hPSCREG), member of the American Society for Human Genetics (ASHG) Task Force on "Gene Editing," Academic Secretary of the International Stem Cell Forum Ethics Working Party, and leader of the Governance Working Group of the International Stem Cell Banking Initiative (ISCB). She contributed to the development of harmonized ELSI and educational tools for Canadian Blood Services' National Public Cord Blood Centre for the Commercialization of Regenerative Medicine (CCRM), and the Bioethics Education Project of the Royal College of Physicians and Surgeons of Canada. With the CGP, she continues to collaborate in four projects related to stem cell research and regenerative cell therapy.



AMALIA ISSA | UNIVERSITY OF THE SCIENCES

Amalia is an internationally renowned scientist in the field of personalized genomic medicine (precision medicine) who founded the Personalized Medicine & Targeted Therapeutics™ Center in 2001, as one of the very first centers focused on pharmacogenomics and personalized medicine. She is also currently a Full Professor at the University of the Health Sciences. She undertook some of the earliest studies of the societal and policy implications of pharmacogenomics, pioneered the science of precision medicine decision-making, and continues to be engaged in leading a multidisciplinary collaborative effort to investigate and address important questions to build and develop the science of personalized genomic healthcare delivery. She is excited to be collaborating on several projects of mutual interest at the CGP, as well as with the Global Alliance for Genomics & Health's Regulatory & Ethics Workstream. Dr. Issa holds leadership positions in several professional associations and national and international scientific advisory committees, and has received many awards and honours for her work. She is excited to be collaborating on several projects of mutual interest at the CGP, as well as with the Global Alliance for Genomics & Health's Regulatory & Ethics Workstream.



HANNA KIM | YONSEI UNIVERSITY

Hannah Kim, M.D., Ph.D., is a research assistant professor at the College of Medicine, Yonsei University and a researcher at the Asian Institute for Bioethics and Health Law. She studied medicine and holds a PhD in healthcare law from Yonsei University. She worked as a Fellow at Department of Medical Law at Yonsei University in 2016–2017. She was a member of the Institutional Bioethics Board in the Severance Hospital, Yonsei University and also a member of the Committee of Direct-to Consumer Genetic Testing under the Ministry of Health and Welfare in South Korea.

With the CGP, she continues to collaborate in genomics data sharing, genome editing and genetic discrimination.



MADELEINE MURTAGH | NEWCASTLE UNIVERSITY

Professor Madeleine Murtagh is Chair in Sociology and Bioethics in the Centre for Policy, Ethics and Life Sciences, Newcastle University. Her transdisciplinary approach is twofold: complementing data science research with ethnographic investigation to evaluate the progress, emergent values, outcomes and social effects of that science; and, development of responsible and responsive data sharing infrastructures for biobanks and cohort studies.



DYLAN ROSKAMS-EDRIS | TANENBAUM OPEN SCIENCE

Dylan works primarily at the intersection of neuroscience, bioethics, and intellectual property. Neuroscience has been revealing the secrets of the nervous system for decades. With modern scanning and neuromodulation techniques this knowledge is now being put to use making tools for manipulating neural activity in ways that not so long ago would have been considered science fiction. As these new capabilities are developed ethical considerations should be forefront throughout the development process, including how and when restrictive intellectual property rights should be used. Dylan's more recent work concerning how open science can be used to make innovation and discovery faster, cheaper, and more accessible builds directly upon his prior work.

Dylan currently lives in Victoria, BC and is working with the CGP on the development of publication and commercialization policies for the Canadian Open Neuroscience Platform.



KYUNGYUN SUNU | YONSEI UNIVERSITY

Kyungyun Sunu graduated from Changchun University with an Honours master of acupuncture in 2009 and is currently a researcher and Ph.D student in Yonsei University Asian Institute for Bioethics and Health Law. Her master's thesis focuses on the interrelation between traditional medicine and genomics. At the CGP, she is working with Yann Joly and Hannah Kim on a project focused on reviewing global use of traditional medicine databases linking with genomics and precision medicine, analyzing the privacy problems in the legal and ethical aspects, and suggesting considerations for promoting responsible use of TM databases in the era of precision medicine in global level.



SUSAN WALLACE | UNIVERSITY OF LEICESTER

Susan Wallace is the Head of the Policymaking Core of the International Working Group on Ethics, Governance and Public Participation of the P3G Consortium. Her research interests include examining the policy implications of population biobanking; the policy implications related to ethics review of human subjects research; public health ethics and public health genetics. She is also Associate Editor of the journal, Public Health Genomics.

Immediately prior to joining the Centre de recherche en droit public (CRDP) at the Université de Montréal, Susan was Policy Officer (Humanities) at the Public Health Genetics Unit, Cambridge Genetics Knowledge Park, in Cambridge, UK. She has also been Director of the Americas Office of the Human Genome Organisation in Bethesda, Maryland, USA. She obtained her Ph.D. in 2004 at the University of Sheffield, Sheffield, UK, in Biotechnological Law and Ethics.



CGP

GUEST SPEAKERS

FEBRUARY **17**

PASCAL BORRY

ASSOCIATE PROFESSOR

of Bioethics at the Centre for Biomedical Ethics and Law of the University of Leuven, Belgium

"Expanded carrier screening: ethical challenges to responsible implementation"

MARCH **14**

PROF. ANYA PRINCE

ASSOCIATE PROFESSOR

of Law and Member of the University of Iowa Genetics Cluster

"The state of genetic discrimination legislation in the US"

MARCH **19**

PROF. METTE HARTLEV

PROFESSOR

of Health Law at the Faculty of Law, University of Copenhagen and head of the research Centre WELMA (Centre for Legal Studies in Welfare Market)

"Big Data, personalized medicine and tensions between autonomy and solidarity in Danish Healthcare"

MAY **10**

HANNAH KIM

PROFESSOR

Department of Medical Law and Ethics, Division of Medical Humanities and Society, College of Medicine, Yonsei University, South Korea

"Once upon a Time at the CGP: A Korean researcher's adventure in the world of genomics and policy"

AUGUST **20**

JONATHAN KIMMELMAN

PROFESSOR AND DIRECTOR

of the Biomedical Ethics Unit and his own research group, STREAM (Studies in Translation, Ethics and Medicine), Faculty of Medicine, McGill University, Montreal, Canada

"Therapeutic value of accessing new drugs in clinical trials"

AUGUST **27**

DR. BRYN WILLIAM-JONES

FULL PROFESSOR AND DIRECTOR

of the Bioethics Program, Department of Social and Preventive Medicine, School of Public Health (ESPUM), University of Montreal, Montreal, Canada

"Ethics, AI and Research Integrity"

SUMMER SEMINAR SERIES

May 28 - August 27, 2019

Each year, the CGP invites its members and Invited Scholars to present to the team and share their research findings (e.g. new publications, ongoing research results, etc). It is a great opportunity to both learn about each other's research projects and be acquainted with emerging issues in different fields. This year, some of the topics ranged from social acceptability of syst-omics approaches to Salmonella fieldwork, GDPR compliance and international health research consortia: practical considerations, the GenCounsel project, human tissue as property: common (law) confusion, simplifying biobank consent forms, unclear licensing of public variant databases, relational autonomy and epigenetics, and ELSI online portals.



LES ENTRETIENS JACQUES CARTIER

November 5, 2019

With a network of more than 70 public and private partners from both sides of the Atlantic, the Centre Jacques Cartier is one of the few organizations that contributes to expand relationships and bring together players for international francophone events. Organized for more than 30 years, each year alternately in Auvergne-Rhône-Alpes (France), and in Canada (Montréal and Ottawa), the *Entretiens Jacques Cartier* (EJC) are the largest gatherings between France and Quebec actors and stakeholders.

This year's EJC, "**A digital shift as a vector for territorial equality in health**", fostered a reflection and discussion on the coming of digital innovation and its legal, ethical and social impact on the healthcare system. The meeting sponsored and organized by Prof. Joly and Zawati from the Centre of Genomics and Policy, and in collaboration with their colleague Me Eric Martinent from the Université Jean Moulin (Lyon), took place at McGill University on November 5, 2019.

Prof. Joly and Zawati, who were also speakers during the event, engaged on issues of how to prepare for learning digital processes in Quebec's healthcare system and accountability of digital innovation. The 2019 EJC provided a great networking opportunity for graduate and articling students and early-career researchers who could meet and discuss with stakeholders, including several healthcare professionals, about the impact of academic research on practices of actors and operators in terms of ethics and care accompanying the implementation of changes.



CCGP

COMPLETED RESEARCH PROJECTS 2019

THE INTERNATIONAL CANCER GENOME
CONSORTIUM (ICGC) DATA ACCESS
COMPLIANCE OFFICE (DACO)
JULY 2009 – SEPTEMBER 2019

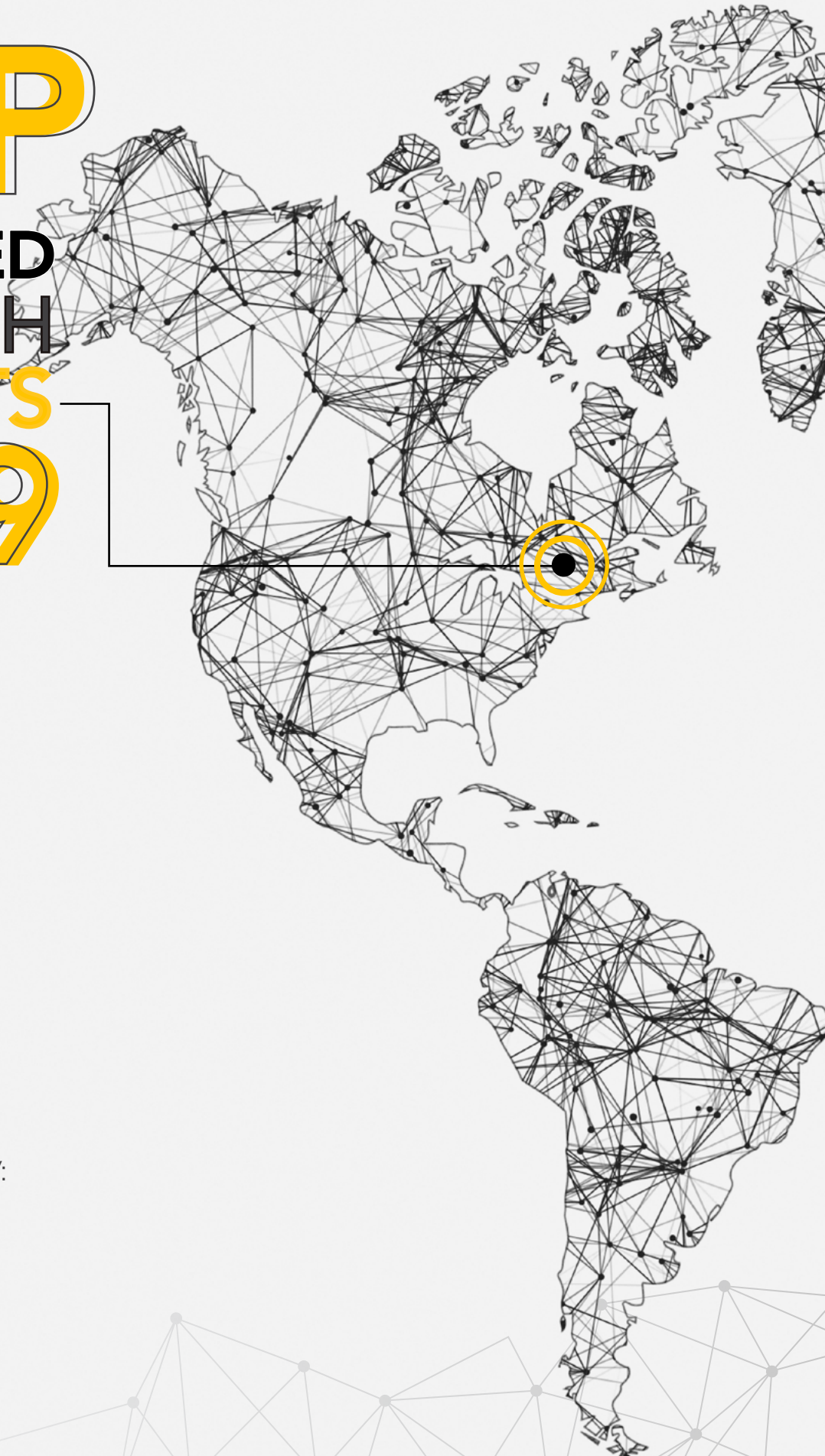
THE CANCER GENOME COLLABORATORY
APRIL 2014 – MARCH 2019

RÉSEAU EN SOINS DE SANTÉ
PERSONNALISÉS-Q-CROC
APRIL 2014 – SEPTEMBER 2019

PRÉDISPOSITION, PRÉDICTION ET
PRÉVENTION DU CANCER DU SEIN
(PRÉ3VENTION)
APRIL 2016 – MARCH 2019

REFORMING CANADIAN STEM CELL POLICY:
MOVING BEYOND THE ASSISTED HUMAN
REPRODUCTION ACT (AHRA)
APRIL 2018 – FEBRUARY 2019

OPEN SCIENCE AND THIRD-COUNTRY
PERSONAL DATA TRANSFERS: "OPEN"
UNLIMITED?
APRIL 2018 – MARCH 2019





NAC BIO

SEPTEMBER 2018 – SEPTEMBER 2019

HEALTHY BRAINS
FOR HEALTHY LIVES OPEN SCIENCE
POLICY KNOWLEDGE MOBILIZATION

SEPTEMBER 2018 – DECEMBER 2019

GENETIC COUNSELLING IN QUEBEC
FOR PRENATAL TESTING FOR INTERSEX
CONDITIONS

SEPTEMBER 2018 – AUGUST 2019

CANADIAN OPEN NEUROSCIENCE PLATFORM
(CONP) – ETHICS AND GOVERNANCE
COMMITTEE; SCHOLARSHIP SUPERVISORS

JANUARY 2019 – DECEMBER 2019

THE INTERNATIONAL CANCER GENOME CONSORTIUM (ICGC) DATA ACCESS COMPLIANCE OFFICE (DACO)

JULY 2009 – SEPTEMBER 2019

Ontario Institute for Cancer Research

The International Cancer Genome Consortium (ICGC) represents international cancer research projects who share the common aim of elucidating genomic changes in a range of cancers. ICGC has gathered mass volumes of data since its inception culminating in the PCAWG publication in Nature (February 5, 2020). Data is shared with 1300 researchers from 37 countries. The CGP houses the consortium's Data Access Compliance Office (DACO). International researchers have obtained access to controlled data for use in genomics, bioinformatics, and related research. The CGP manages the data access process in order to ensure that cutting edge cancer research progresses efficiently and with as broad a reach as possible. To date, DACO has processed over 2000 applications for ICGC Controlled Data Access (including resubmissions and renewals). This project has been realized at the CGP in collaboration with members of the P3G/P3G2 project.

PRINCIPAL INVESTIGATOR
STEIN Lincoln (ICGC Secretariat)

CO-INVESTIGATOR
KNOPPERS Bartha Maria

DATA ACCESS COMPLIANCE OFFICER
ZAWATI Ma'n H.

ASSISTANTS TO DATA ACCESS COMPLIANCE OFFICER
GRAHAM Leah
LEBLANC Camille

ACADEMIC ASSOCIATE
LANG Michael

INVITED SCHOLAR
KIM Hannah

MASTER'S STUDENT
CROCKER Kelsey

PHD STUDENT
SO Derek

RESEARCH ASSISTANTS
LIU Hanshi
BERNIER Alexander

THE CANCER GENOME COLLABORATORY

APRIL 2014 – MARCH 2019

Natural Sciences and Engineering Research Council of Canada (NSERC)

Cancer, a disease of the genome, is the leading cause of mortality in Canada, responsible for more than 70,000 deaths per year. The Cancer Genome Collaboratory is a unique cloud computing facility that is preloaded with more than 500 TB of cancer genomic research data, hosts APIs for efficient access to the data, and provides tools for creating, using and sharing scalable cancer-genome-analysis pipelines. This project aimed to accelerate research for effective treatment of cancer by providing researchers with access to the world's largest open cancer genomics dataset. It accelerated the development of precision oncology, in which the genomes of the patient and tumour inform the choice of the therapy that is most likely to benefit the patient. The project also accelerated our understanding of tumour evolution, allowing tumours to be detected at an earlier stage and for doctors to adjust the therapy as the tumour changes. Over the long term, the project benefited Canadians by providing cancer patients with improved diagnostics and therapeutics. Our Centre was involved in the legal and ethical issues surrounding this project, including questions of privacy and data storage.

PRINCIPAL INVESTIGATOR
STEIN Lincoln

CO-INVESTIGATORS
BADER Gary G.D.
BOUCHARD-CÔTÉ Alexandre
BOURQUE Guillaume

BOUTROS Paul
EL EMAM Khaled
KNOPPERS Bartha Maria
OUELLETTE Francis
SAHINALP Cenk
SHAH Sohrab
SHOICHET Brian

ACADEMIC ASSOCIATE
PHILLIPS Mark

RÉSEAU EN SOINS DE SANTÉ PERSONNALISÉS-Q-CROC

APRIL 2014 – MARCH 2019

Fonds de partenariat pour un Québec innovant et en santé (FPQIS)

The Clinical Research in Oncology Network (Q-CROC) aimed to optimize patient recruitment and enhance the quality of clinical research in oncology. The Q-CROC Network has developed internationally recognized expertise in designing and executing biopsy-driven studies to identify biomarkers in metastatic cancers. As part of this effort, the CGP examined the implications of mobile health (mHealth) for managing patient care and basic health research. Over the course of the project, we sought to develop an understanding of the legal, ethical, and social implications of the adoption of largescale targeted therapeutics-oriented databases and ensuing omics-heavy clinical trials on patient health. In particular, we conducted research on the numerous legal and ethical considerations raised by the increasing application of novel technologies in personalized medicine. Among other things, we ran a study of informed consent processes in health research mediated by mobile health applications and the possibility that such applications may perform broadly clinical functions.

PRINCIPAL INVESTIGATOR
BATIST Gerald

CO-INVESTIGATORS
BÉLANGER Luc
BROCHU Edith

DIAZ Zuanel
GAGNON Martin
JOLY Yann
KNOPPERS Bartha Maria
ROUSSEAU Caroline

ACADEMIC ASSOCIATES
LANG Michael
ZAWATI Ma'n H.

RESEARCH ASSISTANTS
CARON Roxanne
LAGUIA Kristen
OLVERA Elena

PRÉDISPOSITION, PRÉDICTION ET PRÉVENTION DU CANCER DU SEIN (PRÉ3VENTION)

APRIL 2016 – MARCH 2019

Fondation du cancer du sein de Québec
Ministère de l'Économie, de la Science et de l'Innovation (MEIE) CHU Laval

PRINCIPAL INVESTIGATOR
SIMARD Jacques

CO-INVESTIGATORS
ANTONIOU Antonis
AMARA Nabil
BARTLETT-ESQUILAN Gillian
CHAIEB M'Hamed Lajmi Lakhel
CHIQUETTE Jocelyne

The PRÉ3VENTION project focused on the prediction of breast cancer risk. It had several synergistic and complementary components: 1) Identification and validation of rare mutations in new susceptibility genes; 2) Functional validation of the identified variations; 3) Development of a tool for predicting breast cancer risk; 4) Development of tools for communicating breast cancer risk; and 5) Governance of genomic variations banks to support the interpretation of genomic tests. The CGP's involvement in this project was primarily focused on optimizing communication tools (which were developed in previous projects) in order to improve their comprehensibility and acceptability to users. The targeted tools were: the information website for women in the general population, the information website for health professionals, and the BOADICEA breast cancer risk calculation tool. In addition, the CGP participated in identifying liability risks associated with the use of genomic variant databases internationally and in developing best practices in regard to the governance of these databases.

DEVILLEE Peter
DROIT Arnaud
EASTON Douglas
GOLDGAR David
JOLY Yann
KNOPPERS Bartha Maria
LOISELLE Carmen
MASSON Jean-Yves
SCHMUTZLER Rita
van ATTIKUM Haico

ACADEMIC ASSOCIATES
DALPÉ Gratien
HAGAN Julie
LÉVESQUE Emmanuelle
NGUENG-FEZE Ida
THOROGOOD Adrian

RESEARCH ASSISTANT
ESQUIVEL SADA Daphne

REFORMING CANADIAN STEM CELL POLICY: MOVING BEYOND THE ASSISTED HUMAN REPRODUCTION ACT (AHRA)

APRIL 2018 – FEBRUARY 2019

Tri-Council (CIHR/NSERC/SSHRC) and Networks of Centres of Excellence (NCE) Stem Cell Network (SCN)

Scientific developments and their expanding scope demonstrate the need to continue socio-ethical and policy discussions surrounding the fields of stem cells, and genetic and reproductive technologies. Reform of the Assisted Human Reproduction Act (AHRA) remains uncharted. Yet, there is a critical need for policy guidance adaptive to the complexities of "cellular genomics." In 2016, the Canadian Government announced its intention to strengthen and clarify the policy frameworks regulating assisted human reproduction. Consequently, from 2016-2017, the CGP, together with the SCN and other collaborators (the "Policy Group"), sponsored four workshops to assess the adequacy of existing regulatory frameworks. The outcome was a series of peer reviewed publications leading to a Consensus Statement to guide reform of the AHRA. Another outcome was future agenda setting highlighting the necessity to move from policy development to consultation and validation.

We proposed a critical series of interactions with Canadian stakeholders with the objective of consulting and validating our recommendations, to propose effective policy translation. This approach was supported by organizations such as the Canadian Medical Association (CMA), the Canadian College of Medical Geneticists (CCMG-CCGM), governmental agencies (e.g. Health Canada), and academic-industry organizations such as the Centre for Commercialization of Regenerative Medicine (CCRM).

PRINCIPAL INVESTIGATOR
KNOPPERS Bartha Maria

ACADEMIC ASSOCIATES
KLEIDERMAN Erika
NGUYEN Minh Thu

PHD STUDENT
NOOHI Forough

RESEARCH ASSISTANT
TOURÉ Seydina

OPEN SCIENCE AND THIRD-COUNTRY PERSONAL DATA TRANSFERS: "OPEN" UNLIMITED?

APRIL 2018 – MARCH 2019

Tanenbaum Open Science Institute

Open Science is among the most recent branches of the various open content movements to attract widespread attention and significant investment on both sides of the Atlantic. In Canada, the 2017 launch of the Tanenbaum Open Science Institute came with a commitment to forgo intellectual property claims on the data associated with their research, and otherwise make their data broadly available. These initiatives correspond with the lead-up period to the enforcement of the European Union's new General Data Protection Regulation (GDPR), whose rules on the transfer of personal data to countries outside the EU are part of a network of data protection frameworks including Canada's Personal Information Protection and Electronic Documents Act. Because open content movements, including Open Science, have rarely engaged with the implications of data protection on their overarching mission, the risk of contradictory, incoherent, and ill-suited practice and frameworks looms large in this area. The CGP was involved in research aimed at tracing how the values underlying Open Science and data protection might be harmonized in the context of data transfer, and in particular with key transfer frameworks sketched out in the GDPR: adequacy decisions, model contractual clauses, and codes of conduct.

PRINCIPAL INVESTIGATOR
ROULEAU Guy

CO-INVESTIGATOR
KNOPPERS Bartha Maria

ACADEMIC ASSOCIATE
PHILLIPS Mark

GENETIC COUNSELLING IN QUEBEC FOR PRENATAL TESTING FOR INTERSEX CONDITIONS

SEPTEMBER 2018 – AUGUST 2019

McGill Observatory on Health and Social Services
Reforms (MOHSSR)

As our scientific understanding of intersex conditions increases, and as we increase the frequency of testing that can detect intersex conditions prenatally via genetic testing, we will increase awareness of intersex conditions in otherwise asymptomatic individuals. As is true of other biological differences with the potential for prenatal diagnosis, this has the potential to increase pathologization, particularly given the option to terminate affected pregnancies. Genetic counselling is one avenue through which parents might be helped to understand the full spectrum of intersexuality and realistic expectations for their children. Despite a pressing need, policies and regulations for genetic testing and genetic counselling in the context of intersex conditions are severely lacking, and there has not been a commensurate rise in training and education for genetic counselors on this subject.

Of the five genetic counseling training programs available in Canada, two are currently located in Quebec, at McGill University and Université de Montréal. For this research, we investigated the training available for genetic counselors on intersex conditions, as well as the content of genetic tests that permit testing for intersex conditions. Simultaneously, we undertook a scoping review of existing literature and applicable policy recommendations on the communication of prenatal test results involving intersex conditions to parents. Out of this, we have developed a discussion paper drawing attention to the implications of the rise of prenatal genetic testing for intersex individuals.

PRINCIPAL INVESTIGATOR
JOLY Yann

ACADEMIC ASSOCIATE
SAULNIER Katie

NAC BIO

SEPTEMBER 2018 – SEPTEMBER 2019

NAC Bio Inc.

NAC Bio is a health information company aiming to advance clinical research into the medicinal benefits of cannabis in the treatment of chronic disease and illness, by using the latest developments in data-science, human genomics and digital health. Headquartered in Vancouver, British Columbia, it was founded by National Access Cannabis Corp. and by Dr. Tyler Wish.

As part of this project, P3G2 assisted the team in establishing their recruitment process in order to ensure the respect of ethical guidelines. Support on governance, data storage and data sharing issues was also provided.

PRINCIPAL INVESTIGATOR
KNOPPERS Bartha Maria

ACADEMIC ASSOCIATE
TASSÉ Anne-Marie

RESEARCH ASSISTANT
KOAYES Myriam

HEALTHY BRAINS FOR HEALTHY LIVES OPEN SCIENCE POLICY KNOWLEDGE MOBILIZATION

SEPTEMBER 2018 – DECEMBER 2019

Canada First Research Excellence Fund

As part of the Open Science Policy Knowledge Mobilization project, P3G2 has developed an international comparative research brief with a focus on consent. It also designed a consent form seeking to increase patient awareness of and promote data sharing according to open science principles and in line with international best practices.

PRINCIPAL INVESTIGATOR
GOLD Richard

ACADEMIC ASSOCIATE
TASSÉ Anne-Marie

RESEARCH ASSISTANT
KOAYES Myriam

CO-INVESTIGATORS
JOLY Yann
KARAMCHANDANI Jason
KNOPPERS Bartha Maria

**CANADIAN OPEN NEUROSCIENCE
PLATFORM (CONP) – ETHICS
AND GOVERNANCE COMMITTEE;
SCHOLARSHIP SUPERVISION**

JANUARY 2019 – DECEMBER 2019

Fondation Brain Cancer Foundation
Canadian Brain Research Fund

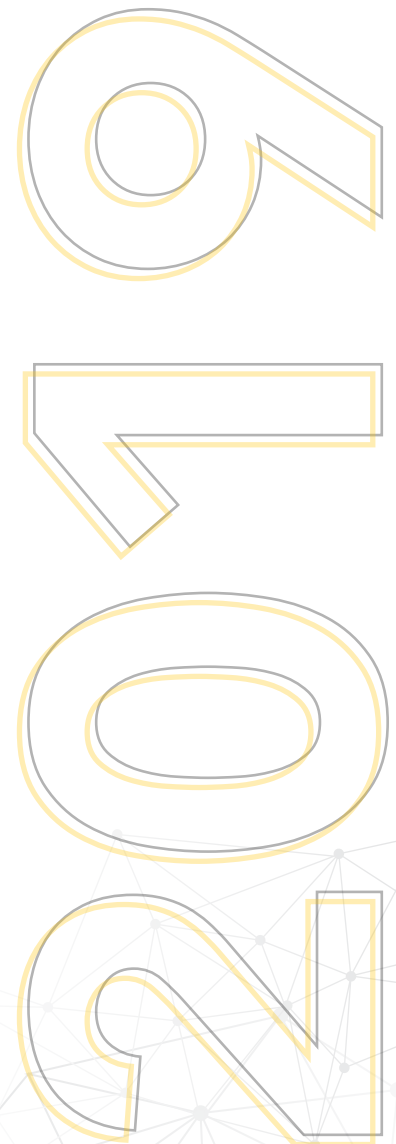
The Canadian Open Neuroscience Platform (CONP) aimed to bring together many of the country's leading scientists in basic and clinical neuroscience to form an interactive network of collaborations in brain research, interdisciplinary student training, international partnerships, clinical translation and open publishing. The platform provided a unified interface to the research community, so as to propel Canadian neuroscience research into a new era of open neuroscience research with: the sharing of both data and methods; the creation of large-scale databases; the development of standards for sharing; the facilitation of advanced analytic strategies; the open dissemination to the global community of both neuroscience data and methods, and the establishment of training programs for the next generation of computational neuroscience researchers. CONP aimed to remove the technical barriers to practicing open science and improve the accessibility and reusability of neuroscience research to accelerate the pace of discovery.

The CGP hosted the Ethics and Governance Committee for the CONP to ensure neuroscience data are shared in a respectful and responsible manner. The Committee was Chaired by Dr. Knoppers and managed by Adrian Thorogood. The Committee has generated an Ethics and Data Governance Framework, as well as Publication and Commercialization Policies to promote responsible open neuroscience, available at conp.ca.

PRINCIPAL INVESTIGATOR
EVANS Alan

ACADEMIC ASSOCIATE
THOROGOOD Adrian

CO-INVESTIGATOR
KNOPPERS Bartha Maria



CCGP

CURRENT RESEARCH PROJECTS

THE QUÉBEC NETWORK OF APPLIED GENETIC MEDICINE
APRIL 2006 – MARCH 2020

ThéCell : RÉSEAU DE THÉRAPIE CELLULAIRE, TISSULAIRE ET GÉNIQUE DU QUÉBEC
APRIL 2009 – MARCH 2020

CANADIAN PARTNERSHIP FOR TOMORROW PROJECT (CPTP)
APRIL 2009 – MARCH 2020

CE IN BIOMARKER-DRIVEN CLINICAL RESEARCH FOR PERSONALIZED MEDICINE IN CANCER (EXACTIS)
APRIL 2014 – MARCH 2020

A Syst-OMICS APPROACH TO ENSURING FOOD SAFETY AND REDUCING THE ECONOMIC BURDEN OF SALMONELLOSIS
OCTOBER 2015 – SEPTEMBER 2020

RESEARCH ADVANCEMENT THROUGH COHORT CATALOGUING AND HARMONIZATION (ReACH)
APRIL 2016 – MARCH 2021

HOW THE EARLY ENVIRONMENT INTERACTS WITH PRENATAL ADVERSITY AND GENETIC SUSCEPTIBILITY TO MODERATE THE RISK FOR ANXIOUS AND DEPRESSIVE DISORDERS FROM INFANCY TO EARLY ADOLESCENCE - THE MODERATING EFFECT OF MATERNAL CARE AND THE MEDIATING EFFECT OF TEMPERAMENT
APRIL 2016 – MARCH 2021

Sino-Canada HeLTI: A MULTIFACETED COMMUNITY-FAMILY- MOTHER-CHILD INTERVENTION STUDY FOR THE PREVENTION OF CHILDHOOD OBESITY (SHeLTI)
APRIL 2016 – MARCH 2021

THE GENDER SPECIFIC EFFECTS OF PRENATAL ADVERSITY ON THE DEVELOPMENT OF ANXIOUS AND DEPRESSIVE PSYCHOPATHOLOGY IN EARLY ADOLESCENCE – THE MODERATING EFFECT OF GENES AND EARLY MATERNAL CARE
APRIL 2016 – MARCH 2021

CANDIG: CANADIAN DISTRIBUTED CYBER-INFRASTRUCTURE FOR GENOMICS
APRIL 2016 – MARCH 2021

PROGRAMME DE RECHERCHE ET D'INNOVATION SUR LES MALADIES RARES (PRISMES)
APRIL 2016 – MARCH 2021

MULTIDIMENSIONAL EPIGENOMICS MAPPING CENTRE (EMC) AT MCGILL
FEBRUARY 2017 – JANUARY 2022

HEALTHY LIFE TRAJECTORIES (HELTI): GOVERNANCE FRAMEWORK
JANUARY 2018 – MARCH 2022

REGULATION OF INTERNATIONAL DIRECT-TO-PARTICIPANT (DTP) GENOMIC RESEARCH
MARCH 2018 – JANUARY 2021

TOWARD EFFECTIVE HEALTH COMMUNICATION WITH INTERSEX CANADIANS: A STUDY OF ETHICAL AND LEGAL CHALLENGES
MARCH 2018 – MARCH 2022

BUILDING A GOVERNANCE TOOLKIT FOR CANADIAN HEALTHY INFANT LONGITUDINAL DEVELOPMENT (CHILD)
APRIL 2018 – MARCH 2020

QUEBEC 1000 FAMILIES (QIK) PROJECT (TRANSFORMING AUTISM CARE CONSORTIUM)
APRIL 2018 – MARCH 2021

PRECISION ONCOLOGY FOR YOUNG PEOPLE (PROFYLE 2)
APRIL 2018 – MARCH 2021

INTERROGATING AND IMPLEMENTING OMICS FOR PRECISION MEDICINE IN ACUTE MYELOID LEUKEMIA
APRIL 2018 – MARCH 2022

GENCOUNSEL: OPTIMIZATION OF GENETIC COUNSELLING FOR CLINICAL IMPLEMENTATION OF GENOME-WIDE SEQUENCING
APRIL 2018 – MARCH 2022

PERSONALIZED RISK ASSESSMENT FOR PREVENTION AND EARLY DETECTION OF BREAST CANCER: INTEGRATION AND IMPLEMENTATION (PERSPECTIVE II)
APRIL 2018 – MARCH 2022

PERSONALIZED THERAPY FOR INDIVIDUALS WITH CYSTIC FIBROSIS
APRIL 2018 – APRIL 2022

CARE4RARE CANADA: HARNESSING MULTI-OMICS TO DELIVER INNOVATIVE DIAGNOSTIC CARE FOR RARE GENETIC DISEASES IN CANADA (C4R-SOLVE)
APRIL 2018 – MARCH 2022

MCGILL UNIVERSITY AND GÉNOME QUÉBEC INNOVATION CENTRE
APRIL 2018 – MARCH 2022

MSSNG DATABASE – DATA ACCESS COMPLIANCE OFFICE
JULY 2018 – JUNE 2021

EPIGENOME-WISE: ETHICAL, LEGAL AND SOCIETAL ISSUES OF NEW ASSAYS FOR DNA-METHYLATION IN CANCER DIAGNOSTICS AND SCREENING
JULY 2018 – APRIL 2020

GENOMICS, ISLAMIC ETHICS AND PUBLIC ENGAGEMENT (GIEPE): TOWARDS BRIDGING THE KNOWLEDGE AND COMMUNICATION GAPS
OCTOBER 2018 – SEPTEMBER 2021

EPIGENOMICS SECURE DATA SHARING PLATFORM
FOR INTEGRATIVE ANALYSES (EPISHARE)

OCTOBER 2018 – SEPTEMBER 2021

EUCANSHARE: AN EU-CANADA JOINT
INFRASTRUCTURE FOR NEXT-GENERATION
MULTI-STUDY HEART RESEARCH

OCTOBER 2018 – SEPTEMBER 2022

HUMAN CELL ATLAS

NOVEMBER 2018 – OCTOBER 2020

CAN-SHARE CONNECT: SUPPORTING THE
REGULATORY AND ETHICS WORK STREAM OF
THE GLOBAL ALLIANCE FOR GENOMICS AND
HEALTH (GA4GH)

JANUARY 2019 – DECEMBER 2022

OBSERVATOIRE INTERNATIONAL SUR LES
IMPACTS SOCIÉTAUX DE L'INTELLIGENCE
ARTIFICIELLE ET DU NUMÉRIQUE

MARCH 2019 – APRIL 2023

PROTECTING PRIVACY IN THE POSTGENOMIC
ERA : ENSURING RESPONSIBLE DATA
GOVERNANCE BY DIRECT-TO-CONSUMER
COMPANIES ENGAGING WITH EPIGENETICS,
MICROBIOMICS AND INTEGRATIVE MULTI-OMICS

APRIL 2019 – MARCH 2020

THE IMPACTS OF THE LACK OF LEGAL
RECOGNITION OF GENETIC COUNSELORS IN
QUEBEC

APRIL 2019 – MARCH 2020

LE DÉVELOPPEMENT D'UNE THÉRAPIE
GÉNÉRIQUE EFFICACE ET SÉCURITAIRE POUR
L'ÉPIDERMOLYSE BULLEUSE RECESSIVE
DYSTROPHIQUE ET JONCTIONNELLE

APRIL 2019 – MARCH 2020

PROJECT ARCHI
(PILOT STUDY OF "PRECINOMICS")

APRIL 2019 – JUNE 2020

CANADIAN GENOMICS PARTNERSHIP FOR
RARE DISEASE (CGP4-RD): POLICY TOOLKIT

APRIL 2019 – MARCH 2021

LE CONSORTIUM QUÉBÉCOIS CONTRE LE
CANCER POUR DE NOUVEAUX AGENTS
THÉRAPEUTIQUES ET BIOMARQUEURS

APRIL 2019 – MARCH 2021

VALIDATING, SPECIFYING & PRIORITIZING
THE ETHICAL, LEGAL AND SOCIAL
IMPLICATIONS OF IMPLEMENTING
ARTIFICIAL INTELLIGENCE WITHIN
ANTI-DOPING STRATEGIES: AN
INTERNATIONAL DELPHI STUDY

APRIL 2019 – MARCH 2021

THE CANCER GENOME COLLABORATORY

APRIL 2019 – MARCH 2023

EUCANCAN: A FEDERATED NETWORK
OF ALIGNED AND INTEROPERABLE
INFRASTRUCTURES FOR THE
HOMOGENEOUS ANALYSIS, MANAGEMENT
AND SHARING OF GENOMIC ONCOLOGY
DATA FOR PERSONALIZED MEDICINE

APRIL 2019 – MARCH 2023

POPALSAC : INITIATIVE DE SCIENCE
PARTICIPATIVE EN RECHERCHE SUR LES
POPULATIONS

MAY 2019 – APRIL 2021

THE QUÉBEC NETWORK OF APPLIED GENETIC MEDICINE

APRIL 2006 – MARCH 2020

Réseau de médecine génétique appliquée (RMGA) du Québec
Fonds de Recherche du Québec - Santé (FRQS)

The RMGA is a Québec network of multi- and trans-disciplinary network of researchers seeking to facilitate both applied research in medical genetics in Quebec and the transfer of new knowledge useful to this population. More specifically, its objective is to support and develop basic and applied human genetic research by creating, managing, and promoting scientific infrastructures and knowledge transfer through health services and interventions for the benefit of the Québec population. The Network has 350 members representing the majority of human genetics researchers in Québec. The RMGA included a Legal and Socio-Ethical Issues Infrastructure at the CGP that considered issues arising from the research activities of the RMGA members and provided ELSI guidance on emerging issues. For example, in 2016, the CGP consolidated a decade of RMGA policies into a prospective Statement of Principles addressing ten different issues raised by research involving human: recruitment of research participants, informed consent, secondary use of data and/or biosamples, privacy and confidentiality, professionalism, conflicts of interest, discrimination and stigmatization, governance of biobank and databases, commercialization and return of results. The Québec Network of Applied Genetic Medicine has also been actively involved in the legal and social debate regarding the federal law on genetic discrimination. The RMGA had notably developed a Position Statement on Genetic Discrimination.

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ThéCell : RÉSEAU DE THÉRAPIE CELLULAIRE, TISSULAIRE ET GÉNIQUE DU QUÉBEC

APRIL 2009 – MARCH 2020

Fonds de recherche du Québec - Santé (FRQS)

Created in 2009, the Québec Cell, Tissue and Gene Therapy Network (ThéCell) focuses on the development of novel cell, tissue and gene therapies to improve patient care in an innovative and sustainable manner. It brings together researchers with diverse expertise in the field of regenerative medicine within Quebec to build a multi-disciplinary team. The Network aims to promote and structure translational research and advance knowledge, technological tools and treatments in regenerative medicine. Prof. Knoppers and CGP members support researchers in their reflection on ethical, legal and social issues (ELSI) raised by the transition from bench to bedside of emerging cell and gene therapies. This comprises two components: 1) Assisting researchers in the development of research protocols (sample governance mechanisms, recruitment and participants' consent processes); 2) Providing support in the regulatory approval process for these clinical trials. The multidisciplinary aspect of the Network makes it possible to consider and integrate ELSI concerning the scientific reality of clinical trials in regenerative medicine.

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CANADIAN PARTNERSHIP FOR TOMORROW PROJECT (CPTP)

APRIL 2009 – MARCH 2020

Canadian Partnership Against Cancer (CPAC)

The Canadian Partnership for Tomorrow Project (CPTP) has enrolled 300,000 Canadians between the ages of 35 and 69 years, who have agreed to be followed for their adult lifetime, to explore how genetics, environment, lifestyle, and behavior interact and contribute to the development of cancer and other chronic diseases. This pan-Canadian project has five participating cohorts (Atlantic PATH, CARTaGENE, Ontario Health Study, Alberta Tomorrow Project, BC Generations Project). Hosted at the Policy Partnerships Project for Genomic Governance (P3G2), the ELSI Standing Committee builds the ELSI infrastructure of the CPTP platform. The goals are to bring together ELSI experts from each cohort and develop relevant policies, documents, and procedures that are needed either by the CPTP or by a specific cohort and to ensure the conformity of the platform with legislation and ethics guidelines so as to prospectively guide the cohorts. The ELSI Standing Committee mandate is broad. It ranges from developing interoperable recruitment, access policies, and procedures to dealing with ethical issues surrounding consent, privacy, data sharing, and proposing governance structures for the CPTP. P3G2 also runs the Access Office (AO) of the CPTP, which reviews access requests from national and international researchers.

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CE IN BIOMARKER-DRIVEN CLINICAL RESEARCH FOR PERSONALIZED MEDICINE IN CANCER (EXACTIS)

APRIL 2014 – MARCH 2020

Networks of Centres of Excellence (NCE)
Canadian Institutes of Health Research (CIHR)
Natural Sciences and Engineering Research Council of Canada (NSERC)
Social Sciences and Humanities Research Council (SSHRC)

PRINCIPAL INVESTIGATOR
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The objective of the project is to create and expand a biomedical ecosystem that overcomes the major rate-limiting steps involved in realizing and expanding biomarker-driven clinical research for personalized medicine in cancer. This will be achieved through: 1) ready access to a collection of engaged patients, their tumors, and clinical data collected in a prospective and longitudinal manner that conforms to the highest standards of ethics and quality; and 2) an advanced program in serial biopsies of metastatic tumors that defines the molecular signature of resistance to new targeted agents allowing the industry to modify the drug or add combinations to overcome or avoid resistance and greatly expand the clinical benefit to patients. The Centre of Genomics and Policy provides a review of the ethical and legal issues while ensuring that consent respects the federal and provincial legal requirements (on re-use of samples, governance, confidentiality, data-sharing, e-consent, risks, etc.). Other considerations reviewed by the Centre concern public-private partnerships.

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A SYST-OMICS APPROACH TO ENSURING FOOD SAFETY AND REDUCING THE ECONOMIC BURDEN OF SALMONELLOSIS

OCTOBER 2015 – SEPTEMBER 2020

Genome Québec
Genome Canada

Each year, there are an estimated 88,000 cases of foodborne illnesses related to the consumption of fresh produce contaminated with Salmonella. The health impacts vary, from minor effects to serious infection requiring medical care or even causing death. Salmonella infection is estimated to cost the Canadian economy as much as \$1 billion annually in terms of medical costs, work absenteeism, and economic losses. Using whole genome sequencing, the research team will develop new tools that will: (1) allow public health officials to better determine the source and treatment of Salmonella illnesses; (2) enable stakeholders along the food supply chain to more rapidly identify and remove contaminated fresh produce from grocery stores and restaurants; and, (3) control the presence of Salmonella on fresh produce. An anticipatory governance approach integrates a consideration of the evidentiary requirements, the economic, legal, ethical, and regulatory implications of supporting such a paradigm shift. More precisely, the CGP team will assess the perspectives of key stakeholders regarding the development, adoption and implementation of the subtyping testing method and the biocontrol. This includes integrating the perspectives of experts (Delphi survey), the general public (national public opinion survey), and a series of interviews with key stakeholders.

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RESEARCH ADVANCEMENT THROUGH COHORT CATALOGUING AND HARMONIZATION (ReACH)

APRIL 2016 – MARCH 2021

Canadian Institutes of Health Research (CIHR)

Increasingly, Canadians are affected by chronic diseases such as cancer, cardiovascular disease, chronic obstructive lung disease, diabetes, and mental illnesses. Many of these conditions have their origins in early life (conception, pregnancy, infancy, and childhood). Canadian pregnancy and birth cohort studies have been implemented to explore hypotheses related to the Developmental Origins of Health and Disease (DOHaD).

The Research Advancement through Cohort Cataloguing and Harmonization (ReACH) initiative was formerly established in 2016 to provide the Canadian research community with the means to leverage and carry out leading-edge collaborative research. The ReACH initiative provides resources in the form of a comprehensive web-based catalogue and a harmonization platform to optimize and expand the use of Canadian pregnancy and birth cohorts data and biological samples. The CGP participated by studying the existing processes addressing sharing, access and data linkage and by performing a comprehensive analysis of the ethical and legal clauses included in the documents used by these cohorts (i.e. consent forms, data sharing policies, governance framework, etc.). The CGP has compared the different clauses and processes to identify similarities and divergences and has notably developed a Points to Consider from an ethical and legal point of view, for access to research databases.

Ultimately, the ReACH initiative will enhance the capacity for collaborative and cross-disciplinary research (outputs generated faster and at a lower cost); expand research perspectives (leverage national and international collaborations); improve quality of research practices; and foster the development of innovative and reliable evidence-based research on the Developmental Origins of Health and Disease.

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HOW THE EARLY ENVIRONMENT INTERACTS WITH PRENATAL ADVERSITY AND GENETIC SUSCEPTIBILITY TO MODERATE THE RISK FOR ANXIOUS AND DEPRESSIVE DISORDERS FROM INFANCY TO EARLY ADOLESCENCE

APRIL 2016 – MARCH 2021

Canadian Institutes of Health Research (CIHR)

The precocious and chronic course of depression makes it the disease with the leading cause of disability, an effect marked by a 2-fold difference in the rate for girls and women as of early adolescence. Precise knowledge of how risk factors interact to predict those at higher risk is lacking. For instance, gender differences in stress response are well documented in early emotional development, but not in later development. Genetic differences in susceptibility to prenatal events are also important. The project gives the opportunity to collaborate in four prolific international longitudinal cohorts to communicate, share and reproduce models and findings about early factors in the prediction of early-age psychopathology. The cohorts in Canada, the U.K., the Netherlands and Singapore include and share measures of genes, maternal care, child psychopathology, and sensitive data with different consent forms, measures, access approaches, laws and regulations. The CGP acts as a collaborator-consultant, supporting the project with analysis, reflections and recommendations that pertain to the ethics and legality of: 1. Safeguarding child genomic data, 2. Sharing data across four national jurisdictions, 3. Maintaining standards of international REB's, and 4. Addressing issues of consent and the need to re-contact child participants once they become adults.

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Sino-Canada HeLTI: A MULTIFACETED COMMUNITY-FAMILY- MOTHER-CHILD INTERVENTION STUDY FOR THE PREVENTION OF CHILDHOOD OBESITY (SChELTI)

APRIL 2016 – MARCH 2021

Canadian Institutes of Health Research (CIHR)
The National Natural Science Foundation of China (NSFC)

The epidemics of obesity and metabolic syndrome related disorders are a major public health concern. Increasing evidence points to the role of early life adverse factors in the developmental origins of the vulnerability to such metabolic disorders. Reducing the risk of overweight and obesity (OWO) from early life stages will produce substantial benefits to decrease population burdens of metabolic diseases. However, current intervention measures remain insufficient to halt the increasing OWO epidemics. Building on our strengths in large birth cohort studies, clinical trials and studies on developmental programming of metabolic disorders, our transdisciplinary Sino-Canadian team will conduct a community-based multi-centre cluster-randomized controlled trial to test the effect of an evidence-based and multifaceted early life-course community family-mother-child interventions package incorporated into the routine pre-conception, prenatal and child care systems on childhood OWO rates in 1-6 year old children in China. The CGP is developing the policies and tools to facilitate the use of the cohorts included in this project. More specifically, the CGP develops the governance framework as well as the data access and biospecimen sharing policy. The tools created by the CGP aim to facilitate policy interoperability and access authorizations as well as streamline the ethical and legal aspects of international collaborative research.

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THE GENDER SPECIFIC EFFECTS OF PRENATAL ADVERSITY ON THE DEVELOPMENT OF ANXIOUS AND DEPRESSIVE PSYCHOPATHOLOGY IN EARLY ADOLESCENCE

APRIL 2016 – MARCH 2021

Canadian Institutes of Health Research (CIHR)

The gender dimorphic effects of prenatal stress are well demonstrated. Girls may be more susceptible to the effects of fetal adversity on fearful temperament, emotional reactivity and internalizing problems. Little research has examined whether gender differences in the case of fetal adversity are maintained in the prediction of anxiety and depression in older children. A landmark study reports that maternal prenatal depression is associated with an increased risk of depressive symptoms in 18 year-old female offspring. It suggests the need to consider the interaction between gender and prenatal adversity and the role of genotype and postnatal environments. Accordingly, gender considerations will be approached as follows: (1) careful examination of gender-based age-specific trends in the development of anxious and depressive psychopathology from preschool through pre-adolescence; (2) the moderation of gender effects for anxious and depressive psychopathology by genetic susceptibility; (3) the role of early maternal care; and, (4) early temperamental signals of vulnerability to anxious and depressive psychopathology. The CGP's role is to design ethical and legal guidelines for: (i) the safeguarding of pediatric genomic data; (ii) the sharing of data across four national jurisdictions; (iii) the maintenance of standards by international IRB's; and, (iv) the consent for data use from children, as they become adults.

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CanDIG: CANADIAN DISTRIBUTED CYBER-INFRASTRUCTURE FOR GENOMICS

APRIL 2016 – MARCH 2021

Canadian Foundation for Innovation (CFI)

PRINCIPAL INVESTIGATOR
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The Distributed Infrastructure for Genomics Data Sharing and Analysis project is divided into four activities. In Activity 1, the CGP will develop a broad Canadian data sharing framework, using the APIs developed under the auspices of the Global Alliance for Genomics and Health (GA4GH). Activity 2 continues the development of GenAP: a computational gateway for data analysis in life sciences that is configured to take advantage of Compute Canada infrastructure. Activity 3 builds a data-sharing platform to allow for the collection of standardized clinical data, dynamic cohorts, and the performance of genome analytics across datasets stored on various Compute Canada nodes, and so as to enable genome-guided clinical trials across Canada. Finally, Activity 4 will establish the Canadian Molecular Profiling in Cancer Trials (CAMPACT) Interchange. Together, the four activities will utilize Compute Canada infrastructure to build a distributed and secure computational framework for the analysis of genomic datasets relevant to human diseases and beyond. The Centre of Genomics and Policy will also contribute to the implementation of the data sharing and privacy policy framework of the International Human Epigenome Consortium (IHEC) as well as that of the GA4GH.

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PROGRAMME DE RECHERCHE ET D'INNOVATION SUR LES MALADIES RARES (PRISMES)

APRIL 2016 – MARCH 2021

Le Centre de recherche du CHU de Québec-Université Laval

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The aim of this project is to improve knowledge of the molecular dysfunctions associated with certain rare diseases. This project aims to : 1) Identify the genetic causes associated with certain rare diseases in children and young adults whose genetic cause has not yet been identified; and 2) obtain a better understanding of the molecular mechanisms involved in the development of these rare diseases. In addition, this project aims to establish a biobank for future research at the national and international levels. In a framework of scientific collaboration, the Centre of Genomics and Policy (CGP) oversees and prepares the ethical documents required for initial approval by the Research Ethics Committee of CHU of the Québec-Université de Laval. Subsequently, the CGP provides support on ethical and legal issues, including changes/modifications to ethical documents or preparation of documents arising from the evolution of the project and the initiation of new collaborators with groups of international research.

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MULTIDIMENSIONAL EPIGENOMICS MAPPING CENTRE (EMC) AT MCGILL

FEBRUARY 2017 – JANUARY 2022

Canadian Institutes of Health Research (CIHR)

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To join global efforts, the International Human Epigenome Consortium (IHEC) has established an Epigenome Mapping Centre (EMC) at McGill University that applies epigenome mapping in order to understand interactions between environment and genome in human blood cells, interprets diseases impacting metabolism using tissue samples, and studies how epigenetic changes can alter function of the brain. The large-scale generation and sharing of human epigenome data present challenges to the informed consent process that are managed first through the integration of existing cohort data with EMC McGill, using a special template developed in conjunction with the Public Project in Genomics and Society (P3G), and subsequently by prospectively developing a model consent template that ensures all IHEC consent, policy, and ethics requirements are met. Throughout this, we will continue to actively participate in discussions on the development of a more comprehensive ethical policy framework at the IHEC level. Both the EMC and Epigenomic Data Coordination Centre (EDCC) projects also involve the development of and support for a bioethics workgroup for the IHEC.

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HEALTHY LIFE TRAJECTORIES (HELTI): GOVERNANCE FRAMEWORK

JANUARY 2018 – MARCH 2022

Canadian Institutes of Health Research (CIHR)

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The HeLTI program was developed by the Canadian Institutes of Health Research (CIHR), Institute of Human Development, Child and Youth Health. The program represents a partnership between CIHR, the South African MRC, the Department of Biotechnology, India, the National Natural Science Foundation of China and the World Health Organization. HeLTI was developed to address the increasing burden of non-communicable diseases (including obesity, diabetes, cardiovascular disease and poor mental health) around the world. There are four separate but harmonized projects that are commencing in Soweto (South Africa), Mysore (India), Shanghai (China), and across Canada. All projects are focused towards developing evidence-based interventions that span from pre-conception across pregnancy and into the postnatal period with a goal improving maternal, infant and child health. The CGP is involved in the development of governance tools to foster international data sharing.

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REGULATION OF INTERNATIONAL DIRECT-TO-PARTICIPANT (DTP) GENOMIC RESEARCH

MARCH 2018 – JANUARY 2021

National Institutes of Health (NIH)

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The proposed study is designed to generate a rich body of data concerning the legal and ethical issues of international Direct-To-Participant (DTP) genomic research using a diverse sample of 31 countries. The aims described below are designed to identify and frame the issues in a way to maximize the utility of the research contributions of the international experts. Ultimately, the goal is to produce well-conceived conclusions and actionable policy options.

Aim 1: Convene three expert working groups of researchers and IRB leaders to identify and prioritize the key issues for a standard questionnaire and template to distribute to the study's 32 international experts on country-specific laws and research ethics.

Aim 2: Distribute the questionnaires to the international experts, consult with and advise them as they prepare their responses to the questionnaires and summaries of country-specific legal and ethical issues, compile and analyze the responses, and draft conclusions and policy options.

Aim 3: Distribute the draft conclusions and policy options to the three expert working groups, international consultants, and advisory board members, and obtain their feedback; analyze the responses and use them to prepare a final draft; write and publish a consensus article presenting the findings of the study; and disseminate the results in presentations to various groups of stakeholders.

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TOWARD EFFECTIVE HEALTH COMMUNICATION WITH INTERSEX CANADIANS: A STUDY OF ETHICAL AND LEGAL CHALLENGES

MARCH 2018 – MARCH 2022

Social Sciences and Humanities
Research Council (SSHRC)

About 1.7% of the population falls under the umbrella of "intersex", with bodies that develop along a spectrum of sex differences. Intersex individuals face egregious human rights violations, discrimination, and stigmatization. In healthcare, this includes unnecessary surgical interventions, the withholding of accurate health information, and an overemphasis of incidental health risks. Qualitative research on which best practices and policies can be based, and which would make it possible to put an end to these prejudices, remains underdeveloped. At present, there is a lack of Canadian-specific guidance or explicit legal protections to guide healthcare providers in their professional relationship with intersex patients.

This project engages two communities of stakeholders: intersex individuals and healthcare professionals (HCPs). The core objectives are to generate qualitative evidence on the experiences of intersex individuals in the healthcare system, and to use this evidence to develop improved standards of care. Following a comparative review of relevant laws and policies, we will conduct a series of semi-structured interviews with intersex adults and their HCPs. From these, the CGP will develop: 1) a guidance document for healthcare practitioners; 2) an issues paper on person-centered research with vulnerable populations; and 3) information sheets for intersex individuals navigating the Canadian healthcare system.

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BUILDING A GOVERNANCE TOOLKIT FOR CANADIAN HEALTHY INFANT LONGITUDINAL DEVELOPMENT (CHILD)

APRIL 2018 – MARCH 2020

AllerGen
National Centres Excellence (NCE)

The development and implementation of an ethically and legally robust governance structure for research biobanks and databases is a pre-requisite to building and maintaining the trust of funders, research participants, research ethics boards, and collaborators. A comprehensive governance framework and related policies not only provide immediate guidance for the managers, researchers, participants and other stakeholders involved in the project, but also fosters a continuous and uniform management of the resource for future prospective uses. Since the financial support of AllerGen to the Canadian Healthy Infant Longitudinal Development (CHILD) Study will soon come to an end, time is of the essence to develop and implement a governance framework to ensure maintenance of the scientific utility, validity and usability of the datasets and biospecimens generated by the CHILD Study, for the future. Currently, datasets and samples collected as part of the CHILD study are heterogeneous and vary across different recruitment sites. The Governance Framework provides a common ethical and policy structure for the future use of these datasets and samples so that the voluntary participation of Canadians is respected.

The purpose of this Governance Framework is to provide a general overview of the core elements related to the management, operations and ethical governance of a health database and, where applicable, an associated biobank. Detailed policies and procedures also accompany this guidance.

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QUEBEC 1000 FAMILIES (Q1K) PROJECT (TRANSFORMING AUTISM CARE CONSORTIUM)

APRIL 2018 – MARCH 2021

Fonds de Recherche du Québec – Santé (FRQS)

Launched in 2018, the Transforming Autism Care Consortium (TACC) network aims to bring together the autism research community in Quebec, by improving access and availability of resources and integrating knowledge into practice. The Quebec 1000 families project (the “Q1K project”) is a TACC network’s flagship project. It provides a platform (database, biobank and registry) to facilitate research by creating a large cohort ASD family trios (proband participant, and first-degree relatives) in families where a child has been diagnosed with an autism spectrum disorder. The CGP is developing a governance framework (which includes relevant policies on privacy, data access, return of research findings, etc.), template consent forms/assent forms and support to research ethics board submission, for the Q1K project.

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PRECISION ONCOLOGY FOR YOUNG PEOPLE (PROFYLE 2)

APRIL 2018 – MARCH 2021

Terry Fox Research Institute

Cancer is the leading cause of disease-related death in children, adolescents, and young adults (CAYA) beyond the newborn period. While the overall survival rate in Canada approaches 88% for all CAYA patients (0-29 years old), the prognosis for those with refractory, relapsed or metastatic (‘hard-to-treat’) disease is grim, and progress has stagnated for many disease groups over the last three decades.

To address this gap, and to make new therapeutic for CAYA patients with hard-to-treat childhood cancers, we participated in the PRecision Oncology For Young peopLE (PROFYLE) program. Overall, the program aims to transform the care of CAYA patients by using next-generation molecular tools and cancer model systems to identify disease and patient-specific biomarkers. The core of PROFYLE consists of real-time molecular profiling to personalize cancer treatment with either existing oncology drugs or repurposed drugs. The project includes the incorporation of new technologies and an emphasis on the evaluation and development of minimally invasive patient-specific biomarkers that can track the patient’s molecular profile over time. The Centre of Genomics and Policy studies questions surrounding access to genetic data by parents and the use of mobile health applications when streamlining recruitment processes.

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INTERROGATING AND IMPLEMENTING OMICS FOR PRECISION MEDICINE IN ACUTE MYELOID LEUKEMIA

APRIL 2018 – MARCH 2022

Genome Canada
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Acute myeloid leukemia (AML) is a leading cause of cancer-related death in young adults and a highly lethal disease in older adults. Most AML patients survive fewer than two years after diagnosis, due primarily to an absence of effective treatment options and an inability to target therapies to genomic risk profiles. The Leucegene project aims to contribute to the more effective targeting of AML treatment according to genomics risk profiles, especially in the case of patients in intermediate risk categories for whom no reliable curative treatment measures exist. Alongside its genetics research objectives, the Leucegene project team will also assemble a ground-breaking prognostic and therapeutic web portal that will make the project's findings widely available to researchers, clinicians, and patients. The CGP will undertake an extensive review of policy instruments adopted for similar functions as well as significant engagement with patients, caregivers, and healthcare providers. These efforts will contribute to the drafting of internal policy guidance for managing the Leucegene portal. At the same time, the CGP will draw on international policy and case law to produce a Good Practices document for informing the development of prognostic and therapeutic web portals in other healthcare contexts.

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GENCOUNSEL: OPTIMIZATION OF GENETIC COUNSELLING FOR CLINICAL IMPLEMENTATION OF GENOME-WIDE SEQUENCING

APRIL 2018 – MARCH 2022

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Genome-wide sequencing (GWS; whole genome or exome sequencing) is a powerful new tool that analyzes a person's entire genetic make-up. However, the information garnered from this type of testing can be overwhelming and may be misinterpreted by non-experts. Genetic counsellors are health professionals that aid patients and families in making informed decisions for this type of testing. However, due to the small number of genetic counsellors in Canada and lack of legal recognition, access to their services is extremely limited. As access to GWS improves and cost decreases, the use of this technology will increase along with the need for genetic counselling. As a result, further exploration of the possible legal recognition of genetic counsellors and key related strategies is necessary.

The CGP oversees policy development for the future legal recognition of genetic counsellors in Canada. Specifically, the CGP will (1) research models of legal recognition available to genetic counsellors; (2) categorize the main tasks performed by genetic counsellors and assess how they translate into legal duties; and (3) convene a pan-Canadian working group comprised of key stakeholders to discuss the feasibility of and potential pathways toward legal recognition.

PERSONALIZED RISK ASSESSMENT FOR PREVENTION AND EARLY DETECTION OF BREAST CANCER: INTEGRATION AND IMPLEMENTATION (PERSPECTIVE II)

APRIL 2018 – MARCH 2022

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This project aims to provide evidence that can significantly expand the benefits of current age-based population breast cancer screening programs by supporting the transition to a risk-based approach. This will enable individualized risk assessment and improve the counseling process by health care providers for women. A large population-based cohort will be assembled to evaluate the acceptability and feasibility of using a new comprehensive risk prediction web tool and a genomic profiling test. The cohort will be followed to determine behavioral, psychosocial and clinical outcomes. Policies will be developed to address the socio-ethical and legal challenges for women, health professionals and decision makers associated with implementing risk-based breast screening. The CGP will provide health authorities with acceptable policies that address emergent socio-ethical and legal issues of the implementation of a personalized risk-based screening approach in Canada. To achieve this, the CGP will examine five issues via a legal and sociological transdisciplinary analysis: 1) Extension of the roles of health professionals; 2) Integration of information technologies to provide timely clinical and informational support; 3) Management of privacy when using BOADICEA with electronic health records; 4) Compliance with federal and provincial regulatory requirements and technology transfer options, and; 5) Information of women on the risks of genetic discrimination and existing protections to mitigate them. The CGP will also support the research team in regard to the ethics approvals required and specific ethical issues associated to the establishment of the research cohort.

PERSONALIZED THERAPY FOR INDIVIDUALS WITH CYSTIC FIBROSIS

APRIL 2018 – APRIL 2022

Genome Canada
Ontario Genomics

Cystic fibrosis (CF) is the most common fatal genetic disease, affecting 4,000 Canadians and 80,000 people throughout the world. The debilitating disease causes difficulties in breathing, lung infections, and digestive disorders and those affected die at a median age of 35 in Canada. Treatments can ease symptoms, but there is currently no cure. Newer drugs can address the underlying genetic defect that causes CF, but only some patients respond positively to them, while others do not. Given the side effects and the high cost of these drugs, there is a pressing need for robust predictors of who will respond to what treatment. Dr. Felix Ratjen (Hospital for Sick Children) and his team are developing predictive tools to help clinicians determine the right medicine for the right patient. The team will examine how genetic factors can help predict individual treatment responses and examine if drug testing on tissue samples can be used to inform the potential clinical response to drugs by each patient. The team will work with industry partners, patient organizations and the Ontario Ministry of Health to integrate these strategies into patient care. The result of the team's work will be a shift toward individualized treatment for CF, assistance for clinicians in making treatment decisions, guidance for policymakers on reimbursement and better health outcomes for patients.

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CARE4RARE CANADA: HARNESSING MULTI-OMICS TO DELIVER INNOVATIVE DIAGNOSTIC CARE FOR RARE GENETIC DISEASES IN CANADA (C4R-SOLVE)

APRIL 2018 – MARCH 2022

Genome Canada
Genome Alberta
Genome British Columbia
Ontario Genomics

To understand unsolved rare diseases (RDs), C4R-SOLVE explores new sequencing technologies and seeks to improve data sharing world-wide, enabling the discovery of new causes of RDs. The goal of C4R-SOLVE, aligned with Canada's national RD strategy, is to fully understand the molecular pathogenesis of unsolved RDs and facilitate timely access to clinical genome-wide sequencing. As part of its activities, C4R-SOLVE will develop a pan-Canadian RD repository (Genomics4RD) to optimize data sharing and analysis. P3G2 developed a governance framework to oversee the Genomics4RD database.

This framework outlines the policies with respect to the creation, management, and use of the Genomics4RD repository. It includes, amongst others, provisions on the identification of eligible participants, core consent requirements (prospective/retrospective), terms of the collection and integration of data from different sources (e.g., genomic data, clinical data, cost data, patient-contributed data, etc.), re-contact options and, where relevant, mechanisms for the return of results. Furthermore, an assessment of legacy (retrospective) datasets to be shared with Genomics4RD and PhenomeCentral was undertaken.

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MCGILL UNIVERSITY AND GÉNOME QUÉBEC INNOVATION CENTRE

APRIL 2018 – MARCH 2022

Genome Canada
Genome Québec

The McGill University and Génomique Québec Innovation Centre is a world class research facility for genomics and proteomics. Founded in 2002, the Centre has developed a world-renowned expertise in complex genetic disorders such as cardiac disease, asthma and Type 2 diabetes, and has become a resource and a networking site for various research initiatives in human health, forestry, infectious diseases, agriculture and environment.

Ambitious projects in recent years are a testimony of the ability of Génomique Québec to provide data of exceptional quality in the pursuit of various genomics studies. The Innovation Centre provides complete DNA and RNA analysis services, from a few samples to several tens of thousands per week. Large-scale genomics and proteomics services at the Innovation Centre are articulated around sequencing (including massively parallel sequencing), genotyping, functional genomics and extraction supported by a solid infrastructure, tools (Nanuq), unique expertise in bioinformatics and nucleic acid extraction. The Innovation Center also hosts the Canadian Center for Computational Genomics (C3G) which offers bioinformatics services. All services work in parallel to provide comprehensive, reliable services to the Québec, Canadian and international scientific community. Located on the campus of McGill University in the heart of Montreal, the Innovation Centre acts as a vast resource of knowledge and technology to the academic and industrial sectors. The CGP provides ongoing ethical and policy consultation on this project.

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MSSNG DATABASE – DATA ACCESS COMPLIANCE OFFICE

JULY 2018 – JUNE 2021

Autism Speaks Inc.

Autism Speaks launched the MSSNG project with the overall goal to store and analyze the world's largest collection of genomes of people with autism and their families. With the goal of sequencing the DNA of 10,000 families affected by autism, MSSNG will help answer the many questions we still have about the disorder. Thanks to the Google Cloud, this vast sea of information is accessible for free to researchers. Scientists from around the world will be able to study trillions of data points in one single database. Already, MSSNG has led to new discoveries about autism and its associated health conditions.

As part of the MSSNG Database project, the CGP is offering Data Access Compliance Office (DACO) services to the MSSNG project. From January 1st to December 31st 2019, DACO processed 30 applications (including renewals).

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EPIGENOME-WISE: ETHICAL, LEGAL AND SOCIETAL ISSUES OF NEW ASSAYS FOR DNA-METHYLATION IN CANCER DIAGNOSTICS AND SCREENING

JULY 2018 – APRIL 2020

Netherlands Organisation for Scientific Research (NWO)
Erasmus Medical Center

Epigenetics is the study of molecular mechanisms for the regulation of gene expression, such as DNA methylation, that switch genes off or on without altering the DNA sequence. The Building Blocks of Life project 'Cut out for the future!' is developing a novel assay (MeD-seq technology) for genome-wide DNA methylation profiling in colon and cervical cancer. This new technology will help to understand the role of DNA-methylation in the pathogenesis of cancer, and may ultimately improve the ability to predict disease progression and treatment outcome in colon and cervical cancer and potentially a variety of other cancers. Due to its unique features epigenetic technology - uncovering potentially modifiable risk factors at high resolution and very low cost - may increase individual autonomy, health and well-being by offering personalised preventive interventions. However, these features also give rise to pressing ethical, legal and societal issues regarding autonomy, informed consent and unsolicited findings, harms & benefits of screening tests, privacy, personal responsibility and solidarity.

Through close cooperation with the BBoL project, the CGP will identify and address ethical, legal and societal issues arising in the early phase of research and development of MeD-seq technology. Moreover, we will anticipate and explore issues that may arise in the future when epigenetic technologies may be introduced into the domain of population screening. We will develop practical guidelines to help investigators, test developers and policy makers to consider these issues in the phase of research & development and in anticipation of its potential implementation in population screening.

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GENOMICS, ISLAMIC ETHICS AND PUBLIC ENGAGEMENT (GIEPE): TOWARDS BRIDGING THE KNOWLEDGE AND COMMUNICATION GAPS

OCTOBER 2018 – SEPTEMBER 2021

Qatar National Research Fund

As genomic medicine and personalized healthcare become increasingly prevalent in the Gulf region, the public and policymakers face difficult ethical questions. Since 2003, there has been a great deal of institutional emphasis on developing genomic medicine and personalized healthcare in the Gulf. As healthcare systems increasingly emphasize these emerging fields, the public should be exposed both to the science of genomic medicine and to associated issues in Islamic ethics. The latter, being a crucial element of the public's 'moral world,' underscores how ethics and policy norms may be developed for the regulation of genomics practices within the Islamic tradition.

There has been little scholarly or public debate on the implications of genetics on Islamic ethics. To address these gaps, this project attempts to develop an understanding of public engagement for the development of policies and regulations in the genomics and personalized medicine contexts that is both religiously and culturally sensitive. As a long-term objective, the project aims to lay the foundation for a Qatar-based consortium of experts and specialists interested in fostering public understanding and engagement with science. This project's research team will be composed of experts in such fields as Islamic ethics, genomics, international bioethics, medical social sciences, translation, and interdisciplinary and intercultural communication. The Centre of Genomics and Policy will perform a comparative analysis of international genomics norms that will provide the team with international perspectives they can emulate.

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EPIGENOMICS SECURE DATA SHARING PLATFORM FOR INTEGRATIVE ANALYSES (EPISHARE)

OCTOBER 2018 – SEPTEMBER 2021

Genome Canada
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Advances in next-generation sequencing have led to a vast increase in available human epigenetic data, including transcriptomic data (via RNA-seq) and chromatin data (via ChIP-seq). These epigenetic datasets have led to the development of expression-wide association studies (EWAS) and chromatin-wide association studies (CWAS). This may lead to improved biomedical applications by providing mechanistic explanations and key insights into the interpretation of genome-wide association studies (GWAS). However, obtaining the raw data stored at multiple controlled access repositories can be a very challenging task, because access needs to be controlled in order to protect research participants' right to privacy.

We need mechanisms to make the process of analyzing epigenomic data more flexible, while addressing the ethical and privacy aspects of data sharing. The Global Alliance for Genomics and Health (GA4GH) has developed tools and standards to address these issues for genomic data. Such tools are now also needed for epigenomic data. The EpiShare framework will provide a user-friendly web resource for scientists to access and visualize large epigenomics datasets, alongside privacy and confidentiality assessment tools to ensure that the methods with which the data will be stored, accessed and analyzed meets requirements set by international laws and standards.

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EUCANSHARE: AN EU-CANADA JOINT INFRASTRUCTURE FOR NEXT-GENERATION MULTI-STUDY HEART RESEARCH

OCTOBER 2018 – SEPTEMBER 2022

Canadian Institutes for Health Research (CIHR)
Fonds de Recherche en Santé (FRQS)

H2020 euCanSHare aims to build the first one-stop-shop platform for multi-cohort cardiac data integration and exploitation, integrating within a unified ecosystem metadata catalogues, computational tools and data models for facilitating data sharing and re-use in cardiovascular research. Through this consortium, the platform will build upon existing collaborative initiatives on both sides of the Atlantic, namely the Canadian Alliance for Healthy Hearts and Minds (8 cohorts), the European BiomarCare project (>30 cohorts), and other large cohorts such as the UK Biobank (500,000 participants). Addressing their current limitations and exploiting the accumulated know-how and experience, euCanSHare will provide new possibilities for personalised medicine research in the field of cardiology. As the leaders of WP1 (Socio-ethical and legal interoperability analysis) (and in collaboration with P. Borry (KU Leuven)), P3G2 coordinates the ELSI research activities regarding the legal and ethical implications of implementing blockchain technology, and associated smart contracts, in a Canadian-European data sharing context. The Centre of Genomics and Policy has contributed to this initiative by translating patient consents into automatable profiles for machine reading and providing guidance on Canadian privacy law and research ethics.

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HUMAN CELL ATLAS

NOVEMBER 2018 – OCTOBER 2020

The Chan Zuckerberg Initiative
The Leona M. and Harry B. Helmsley Charitable Trust
The Klarman Family Foundation

The Human Cell Atlas (HCA) is a global biomedical research collaboration to create a reference map of all human cells – an international, public resource for better understanding human health and disease. The HCA's success relies on the expertise of researchers across several countries, undertaking work in different research domains and settings.

The CGP hosts the HCA ethics policy platform and assists the HCA in the ongoing coordination of its Ethics Working Group (EWG), the development of an ethics and data governance framework, template consent forms, relevant tools (retrospective consent filter, ethics submission guidance), template agreements (material/data transfer agreement templates, data submission agreement template, data use agreement template) and a helpdesk to support the HCA community.

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CAN-SHARE CONNECT: SUPPORTING THE REGULATORY AND ETHICS WORK STREAM OF THE GLOBAL ALLIANCE FOR GENOMICS AND HEALTH (GA4GH)

JANUARY 2019 – DECEMBER 2022

CIHR
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In partnership with numerous universities and colleges, and with the support of 88 research centres, non-governmental organizations, businesses, government players and various groups in Quebec, Canada and abroad, Université Laval proposes to set up the International Observatory on the Societal Impacts of Artificial Intelligence and Digital Technologies (OBVIA). The ambition of this innovative institution is to distinguish itself internationally through the quality of its research, its ability to federate various types of expertise and its ability to foster collaboration among all parties concerned by the challenges posed by the development of artificial intelligence (AI) and digital technology. OBVIA is based on four different but interdependent functions. It will conduct intersectoral and interdisciplinary research and creative activities on several priority themes. Members from the CGP will be involved in the “Éthique, gouvernance, démocratie et responsabilité sociale des organisations” Pillar within OBVIA.

OBSERVATOIRE INTERNATIONAL SUR LES IMPACTS SOCIÉTAUX DE L'INTELLIGENCE ARTIFICIELLE ET DU NUMÉRIQUE

MARCH 2019 – APRIL 2023

Fonds de recherche Santé Québec (FRQS)

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PROTECTING PRIVACY IN THE POSTGENOMIC ERA : ENSURING RESPONSIBLE DATA GOVERNANCE BY DIRECT-TO-CONSUMER COMPANIES ENGAGING WITH EPIGENETICS, MICROBIOMICS AND INTEGRATIVE MULTI-OMICS

APRIL 2019 – MARCH 2020

Office of the Privacy Commissioner of Canada

Over the past few years, epigenetic and microbiomic tests have been commercialized by private companies, some of which are currently being advertised and offered to the Canadian public online. The collection and use by private companies of such biological information raises serious legal and ethical privacy concerns. The privacy implications raised specifically by the increase in diversity of these new forms of biological data – and their integration with genomic datasets – have not been seriously addressed yet. This project will investigate the privacy issues emerging from the rapid scientific development and commercialization of what the researchers call “postgenomic biometrics.”

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THE IMPACTS OF THE LACK OF LEGAL RECOGNITION OF GENETIC COUNSELORS IN QUEBEC

APRIL 2019 TO MARCH 2020

Réseau de médecine génétique appliquée
du Québec (RMGA)

As genomic medicine is increasingly used in the clinic, demand for genetic counselling is growing. Genetic counselling, however, is not regulated in most Canadian provinces, including Quebec. Understanding the potential impacts of this lack of regulation on the provision of health services, on the clinical uptake of genomic research findings, and on the risks incurred by the public is essential. The existence of frameworks regulating the practice of a medical profession is one of the options for safeguarding the protection of the public by reserving the acts and titles of specific health professionals. To determine how the activities of a genetic counsellor could be translated into legal duties, our project aims to categorize the main tasks of genetic counsellors and the risks associated with these tasks in the context of Quebec. To do this, we combine our legal expertise, the expertise of an Expert Advisory Committee composed of RMGA members and a broader stakeholder consultation (e.g., genetic counsellors, medical geneticists, and other medical specialists). Understanding the scope, limits and possible overlap of genetic counselling with acts currently reserved for other health professionals will optimize the integration of genetic medicine applied to the practices and policies of the Quebec health system.

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LE DÉVELOPPEMENT D'UNE THÉRAPIE GÉNIQUE EFFICACE ET SÉCURITAIRE POUR L'ÉPIDERMOLYSE BULLEUSE RECESSIVE DYSTROPHIQUE ET JONCTIONNELLE

APRIL 2019 – MARCH 2020

Fonds de recherche Santé Québec (FRQS)
ThéCell

Epidermolysis Bullosa (EB) is a genetic disease manifested by a lack of adhesion between the dermis and the epidermis. It causes detachment of the mucous membrane and epidermis, which can lead to serious complications such as ulcers, infections and cancer (carcinoma). Currently, the treatments offered are palliative, mainly with bandages to protect epithelial wounds. EB is characterised by mutations in different genes. The aim of the project is to develop an effective gene therapy treatment for two types of EB: dystrophic EB (D) and junction EB (J). Skin substitutes (reconstructed skin) will be produced from EB patient cells, grown in vitro and corrected by gene therapy. The efficacy of this treatment will be tested on reconstructed human skin in the laboratory. The CGP will be reviewing ethical and legal issues associated with this project.

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PROJECT ARCHI (PILOT STUDY OF "PRECINOMICS")

APRIL 2019 – JUNE 2020

Ministère de l'Économie et de l'Innovation

ARCHI is the pilot phase of a national platform (PRECINOMICS) for centralized access and exchange of genomic and administrative health data for health research purposes. As a project, ARCHI aims to 1) integrate data from 20,000 participants enrolled in two separate research cohorts (the Montreal Heart Institute and the Canadian Partnership for Tomorrow Project); and 2) enrich these data with (gen)omics data. In addition, doubling as a proof-of-concept, the completion of ARCHI will demonstrate the maturity of data processing and sharing technologies as well as the feasibility of data sharing for precision medicine research.

In this project, the role of the CGP is twofold. First, it is to develop the access and consent governance policy for the platform. To do so, the CGP will survey existing and proposed biobank consent forms and access policies in order to identify regulatory, ethical and governance-related issues and barriers in the access model of the platform. Second, the CGP will develop the privacy and security policy for the platform. Similar to the access and consent governance policy, the CGP will sequentially survey current and proposed best practices in the data sharing ecosystem and propose recommendations matching the profile and orientation of the platform.

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CANADIAN GENOMICS PARTNERSHIP FOR RARE DISEASE (CGP4-RD): POLICY TOOLKIT

(APRIL 2016 – MARCH 2021)

Genome Canada
Genome Québec

With rare diseases (RD), sufficient patient numbers are not available at any one site. Data needs to be centralized, integrated and broadly accessible to drive RD research for gene identification and understanding. Harmonized policies, an overarching governance framework and the sharing of data through a nation-wide data sharing resource would make a significant impact on research and treatment of RDs. The Canadian Genomics Partnership for Rare Diseases (CGP4-RD) Policy Toolkit aims to address disparities between current institutional, provincial and federal regulatory frameworks to foster sharing of research and health data. Building from a stakeholder engagement process, a set of broad, inclusive and actionable policy resources are being developed for implementation by Genome Canada funded Genomic Applications Partnerships Program (GAPP) projects. This policy toolkit also aims to enable pan-Canadian data sharing by projects funded by the Genome Canada GAPP initiative that would incorporate the data sharing principles and practices as well as the protection of patient interests particular to rare diseases. Though tailored to the rare disease clinical research community, the tools developed by the CGP4-RD Policy Toolkit can be adapted and used as models for common diseases as we move towards precision medicine.

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LE CONSORTIUM QUÉBÉCOIS CONTRE LE CANCER POUR DE NOUVEAUX AGENTS THÉRAPEUTIQUES ET BIOMARQUEURS

APRIL 2019 – MARCH 2021

ONCOPOL

Our goal is to create one of the most dynamic North American centres for oncology research and innovation. Based on alliances established between six of the largest oncology hospitals and research centres at McGill University and Université de Montréal, the Quebec Cancer Consortium (QCCC) will be one of the most important oncology innovation poles in North America. Collectively, the CQC will harness the power of databases of more than 16,000 cancer patients each year. The consortium will leverage investments from the Terry Fox Research Institute and several pharmaceutical partners, and will integrate unique oncology platforms, advanced clinical trials, the Rossy Cancer Network, the FRQS-Cancer Network, Oncopole, as well as the Exactis Innovations and C3i National Centres of Excellence, in order to innovate in the implementation and sustainability of precision medicine for the treatment of cancer patients in the Quebec health system. The CGP will be involved in the development of governance tools for the project.

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VALIDATING, SPECIFYING & PRIORITIZING THE ETHICAL, LEGAL AND SOCIAL IMPLICATIONS OF IMPLEMENTING ARTIFICIAL INTELLIGENCE WITHIN ANTI-DOPING STRATEGIES: AN INTERNATIONAL DELPHI STUDY

APRIL 2019 – MARCH 2021

Fonds de recherche du Québec (FRQ)
Ministère de l'Économie et de l'Innovation (MEI)

Our research question aims to validate, specify and prioritize the potential ethical, legal and social implications (ELSI) associated with the introduction of artificial intelligence (AI) within the World Anti-Doping Agency's (WADA) anti-doping strategies. This will be accomplished using a consensus-building approach whereby the perspectives of a group of experts with varied expertise will converge onto a forward-looking approach for the ethical application, regulation and design of AI within an anti-doping context.

Our study's main objective, as stated earlier, is to assess the potential benefits of, challenges with and solutions for an ethically responsible implementation of AI within anti-doping strategies, according to experts from around the world engaged in related administrative, professional, research and advocacy activities. This main objective will be attained by: a) validating existing theoretical expectations and concerns surrounding AI with expert opinion; b) specifying the ELSI raised by the introduction of AI in the particular context of anti-doping; and c) prioritizing the ELSI based on their level of importance, according to our panel of experts.

Ultimately, we aim to better inform and facilitate the translation of the relevant ELSI into normative guidance (i.e. ethical principles and legal norms), as well as shape regulatory and governance approaches in the applications of AI within anti-doping strategies. This will foster coherence and provide overarching ethical guidance to effectively navigate and address the issues and challenges identified.

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XU Handi

THE CANCER GENOME COLLABORATORY

APRIL 2019 – MARCH 2023

Canadian Foundation for Innovation (CFI)

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SHAH Sohrab
SIMPSON Jared

The Cancer Genome Collaboratory (CGC) is a unique Canadian cloud compute facility that holds the world's most comprehensive public collection of cancer genomes and associated clinical information. The proposed work will extend the CGC's data holdings, improve accessibility to the data, add a series of high-quality vetted pipelines for standardized cancer genomics analysis, and implement services that apply new cutting-edge algorithms for the interpretation of cancer genomes. Our design and implementation plans are based on feedback from our Canadian and international user community, and on our own hands-on experience coordinating international genome analysis projects across petabyte-scale data sets. The CGP will be involved in the ethical and policy questions surrounding the sharing of data and the use of e-tools to facilitate adjudication processes.

ACADEMIC ASSOCIATE
PHILLIPS Mark

RESEARCH ASSISTANT
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EUCANCAN: A FEDERATED NETWORK OF ALIGNED AND INTEROPERABLE INFRASTRUCTURES FOR THE HOMOGENEOUS ANALYSIS, MANAGEMENT AND SHARING OF GENOMIC ONCOLOGY DATA FOR PERSONALIZED MEDICINE

APRIL 2019 – MARCH 2023

Canadian Institutes for Health Research (CIHR)
Fonds de Recherche du Québec - Santé (FRQS)

PRINCIPAL INVESTIGATOR
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EUCanCan aims to federate existing European and Canadian infrastructures to analyze and manage genomic oncology data. Each member projects, in Amsterdam, Barcelona, Berlin, Heidelberg, Paris and Toronto, has established a strong genomic oncology research and clinical program. EUCanCan will provide oncology researchers with a uniform computing environment to securely share and analyze harmonized cancer genome and phenome data in the context of clinical research. The CGP is co-leading the development of guidance and ethico-legal tools regarding international sharing of clinical and research oncology data. The aims are to (1) perform a legal, policy, and literature review to develop guidance aimed at Canadian oncology projects when sharing personal health data with European countries and within Canada, (2) analyze the requirements Canadian projects will have to satisfy pursuant to the EU General Data Protection Regulation when receiving personal health data from European partners, (3) delivering a Report these first two topics, (4) developing overarching guidance for the project on the use and sharing of clinical cancer-related genomic and other health related data, and (5) describe generalized compliance tools to be used by future international collaborations, whether they are studying cancer or other diseases.

POPBALSAC : INITIATIVE DE SCIENCE PARTICIPATIVE EN RECHERCHE SUR LES POPULATIONS

MAY 2019 – APRIL 2021

Fonds de la recherche en sante du Quebec (FRSQ)

PRINCIPAL INVESTIGATOR
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CO-INVESTIGATORS
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VÉZINA Hélène

COLLABORATOR
ZAWATI Ma'n H.

This project aims to conceptualize a participatory science platform, popBALSAC, for the collection, sharing and popularized interpretation of population research results. As the platform is built around the recruitment of participants, who provide personal and sensitive data, it is important to reflect on the ethical aspects of such an initiative. Beyond the guiding principles (TCPS) that dictate good practices to be adopted in the framework of genetic research, it is necessary to assess the degree of public awareness of the use of genetic data.

The Centre of Genomics and Policy (CGP) is contributing its experience gained over the last few years to define the scope of the project and the ethical and legal limits to be respected. Led by Dr. Yann Joly, a bioethics research professional from the CGP has documented protocols for accessing and sharing data (genetic data and research results) among the parties involved and participated in the drafting of a guide outlining approaches for managing protocols and ethical consent models.

CGP RESEARCH AWARDS

CANADA RESEARCH CHAIR IN LAW AND MEDICINE



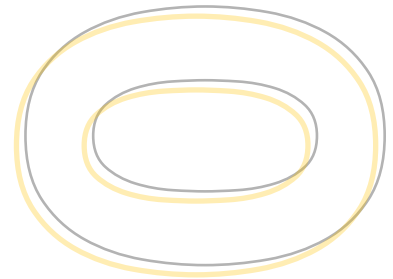
Chaires
de recherche
du Canada

Canada
Research
Chairs

Canada

PROF. BARTHA MARIA KNOPPERS, Ph.D.

Holder of this Tier 1 Chair since the year 2001, the ensuing research program supports the full breath of CGP projects. In particular, it serves to ensure the update and maintenance of the HumGen database, the participation of trainees in national and international conferences and our Invited Scholars program. From 2013 to 2015, it also supported the Framework and policy work of the Regulatory and Ethics Working Group of the Global Alliance for Genomics and Health (GA4GH). The Chair will work on establishing models for data access that take into account the different levels of data sensitivity and use in order to streamline the process and reduce delays.



PROF. YANN JOLY, D.C.L. (Ph.D.), Ad.E.

Designated as “Chercheur boursier niveau Junior 2” since July 2015, the awarded research grant will contribute to the development of a new type of infrastructure covering specific categories of diseases moving the translational domain closer to the clinic (eg. Q-CROC, Biobank Cohort of hospital ICM and Hepatopancreatobiliary (HPB) and Transplant Biobank Research at McGill University). These facilities are used to conduct research, monitor patients in real time and inform therapeutic discoveries (choices) or treatments relevant to the patient’s specific genetic profile. This research grant will allow the conception of legal and ethical policies needed to establish optimal translational research infrastructure for safe, patient centered personalized medicine in Québec.

RECHERCHE TRANSLATIONNELLE EN MÉDECINE PERSONNALISÉE, PERSPECTIVES ET ENJEUX POUR LE QUÉBEC FONDS DE RECHERCHE DU QUÉBEC – SANTÉ (FRQS)

Fonds de recherche
Santé

Québec 

COURSES

**HGEN
660B**

GENETICS, ETHICS AND LAW

Instructor: Prof. Yann Joly, D.C.L. (Ph.D.), Ad.E.

This objectives of this course were:

1) Introduce students to legal, ethical, and policy scholarship in genetics and related “omics” disciplines; 2) promote interdisciplinary collaboration and debate as a means of enriching scientific practices; 3) enable students to develop analytical research skills and to identify and critically evaluate the legal, ethical and policy issues that arise in genetic research and in clinical genetics.

The classes were taught in seminar style, complemented by thematic class discussions and case studies. Themes covered in this course included, but were not limited to: genetic testing, genetic counseling, personalized medicine, privacy and confidentiality, population genetics, regenerative medicine, commercialization and intellectual property, genetic discrimination, and genetic analysis of social and behavioral traits. Through class lectures, case studies and discussions on a series of selected readings, students were asked to reflect on the complex relationships between science, law, and ethics. Each member of the class participated and contributed to the learning that occurred. Such a collaborative learning experience was reflected in the way that the course was structured and the way in which the student’s work was evaluated.

RESEARCH INTERNSHIP IN GENOMICS AND POLICY

Instructor: Prof. Ma'n H. Zawati, D.C.L. (Ph.D.)

**HGEN
674**

The Research Internship in Genomics and Policy course aimed to provide 1 to 2 graduate students in the Human Genetics program with an opportunity to do research on the ethico-legal and policy issues in human genetics. More specifically, graduate students were 1) introduced to the ethical, legal, and policy issues in human genetics in both the research and clinical settings; and 2) familiarized with social science research methodologies, especially international comparative analysis of normative policy and legal instruments. As an internship, these objectives were achieved through active research under the supervision of a mentor working in the student’s area of interest. Specific areas of research at the Centre of Genomics and Policy included but were not limited to: population genomics, biobanks, stem cells, reproductive technologies, paediatric genetic research, data protection, direct-to-consumer genetic testing, gene therapy, personalized medicine, and genetic counseling. Interested students were encouraged to explore the CGP website (www.genomicsandpolicy.org) to identify areas of interest. Undertaking an internship at the Centre of Genomics and Policy allowed students to benefit from a close collaboration with experts at the crossroads of the ethico-legal, medical, and policy fields.

CGP INTERN STUDENTS

The CGP has proposed summer internships for two CMEL LLM students per year, providing one month supervision at CGP with appropriate mentorship and training anticipated to begin in the Summer of 2019.



HANSHI LIU

"My internship experience working at the CGP has been both eye-opening and highly educational. As an intern, I had the opportunity of working with experts at the forefront of their field such as Dr. Yann Joly and learning from them on their work at the intersection of technology, law, and policy. This experience gave me a newfound respect for the multifaceted multidisciplinary nature of science and law in the 21st century. The CGP offered a great environment for learning with supervisors giving helpful feedback and help setting deliverable goals in your field of interest. Overall, there was a lot of autonomy in goal pursuit, and this gave me a distinctly different experience compared to a typical classroom setting that was highly valuable."

HGEN 396, HGEN 674

ELISABETH OLIVIERO

"As an intern, I had the opportunity to work with Dr. Gratien Dalpé (along with supervisor Dr. Yann Joly) to delve into the examination of the ethical, legal, and social implications of genetic discrimination in Canada. Using qualitative methods, my project focused on exploring the public's perceptions of genetic discrimination in online discussion forums. Not only did I enhance my independent research skills, but I also gained a deeper perspective of the pervasive and multifaceted challenges of emerging genetic technologies."

HGEN 674



KAREN YAO

"Working as an intern at the Centre of Genomics and Policy has given me the chance to research and write about topics that intersect in medicine, law, and ethics, which are new and fascinating for me. But above all, it's a great learning environment where I've had the chance to meet and work with collegial intellectuals in an array of multidisciplinary fields."

MCGILL LEGAL CLINIC



ALEXANDER BERNIER

"Articling at the Centre of Genomics and Policy has allowed me to engage with ethical and legal issues at the intersection of conventional healthcare delivery and technological innovation. I have had the opportunity to be part of a well-rounded, multidisciplinary team, and had the chance to interact with stakeholders across academic, medical, and industry settings. I have also been able to participate in data governance, technology regulation and research oversight. The Centre of Genomics and Policy has encouraged me to engage with the practical aspects of healthcare governance and the broader social values that underlie such practice. From the rich intellectual insights of my colleagues and mentors, I have learned to face new challenges with autonomy, compassion, and pragmatism." **Law Society of Ontario**

MICHAEL LANG

"I completed a term of articles for the Law Society of Ontario at the Centre between September 2018 and July 2019 and was called to the Bar in September. Under Professor Ma'n Zawati's supervision, I worked on issues at the intersection of law, medicine, and ethics, including the ways that digital technologies are changing the relationships physicians have with their patients. I learned a great deal about professional responsibility, practice ethics, and the important role that lawyers can play in advancing medical research and contributing to a robust healthcare system." **Law Society of Ontario**



DIMITRI PATRINOS

"As an articling student for the Law Society of Ontario at the CGP, I enjoy the multidisciplinary of the work that I do. Coming from both a legal and scientific background, I enjoy that my research not only draws upon legal perspectives, but also touches upon bioethics, genomics, and public policy." **Law Society of Ontario**

MIRIAM PINKESZ

"Completing my articling program at the CGP offered me the opportunity to delve into various aspects of the law, each teaching me something new and valuable. The supportive and fast-paced environment helped me hone my legal, interpersonal, and academic skills, and pushed me to think outside the box. I am grateful for articling at the CGP, and will take the valuable lessons I learned throughout my legal and academic career." **Law Society of Ontario**



WYNG FOUNDATION

Thanks to a collaborative agreement with the Centre for Medical Ethics and Law of the University of Hong Kong (CMEL) and the WYNG Foundation, we are pleased to support the CGP / Wyng Trust Visiting Scholars Program.

VISITING SCHOLAR PROGRAM

University of Hong Kong



This year, the research of our Visiting Scholars was dedicated to the emerging topics of (i) policy and regulatory responses to new genomic and reproductive technologies, (ii) human enhancement and (iii) gene editing. Prof. Bartha Knoppers organized and hosted an international think tank, "Legal Boundaries on the 'Human' in Humanity", which took place June 9-11, 2019, in Montreal (Canada) with scholars from the CGP, Stanford University (USA), Duke University (USA), Dartmouth University (USA), University of Cambridge (UK), PHG Foundation (UK), University of Wisconsin (USA), University of Edinburgh (Scotland), University of Ottawa (Canada), University of Alberta (Canada), Mannheim University (Germany) and University of Hong Kong (China).

The purpose of this international think tank was to exchange on the forefront of the legal classification/categories applied to human genome research (e.g. genetic editing, privacy), human brain research (e.g. brain enhancement, brain death) and on the use of human body parts and cells in research (e.g. property rights, embryos). This initiative focussed on how legal systems currently respond to bioscientific advances that blur classical, binary legal boundaries between human beings and other living organisms, between living and dead human beings and between human and non-human tissues and cells. These discussions were followed by a Policy Forum paper aiming to provide classification and a potential governance framework by Profs. Bartha Knoppers and Henry T. Greely published in *Science* ("Biotechnologies: nibbling at the legal 'human'" (2019) 366:6472 *Science* 1455–1457).

The CGP would like to thank the WYNG Foundation for its support of this research and think tank.



GENETIC DISCRIMINATION OBSERVATORY (GDO)

More than twenty years after the Universal Declaration on the Human Genome and Human Rights alerted the international community of the need to prevent discriminatory use of genetic information, namely genetic discrimination (GD), this issue still remains pervasive. Because genomic information is now shared across national boundaries by researchers and private companies, better integrated laws, regulations, practices as well as innovative public communication strategies are needed to prevent GD and reduce concerns so that people can avail themselves of novel genetic and computational biology technologies without fear of GD. In 2018, we launched the world's first Genetic Discrimination Observatory (GDO), a collaborative online platform created to prevent GD in Canada and internationally.

A UNIQUE NETWORK

The Genetic Discrimination Observatory (GDO) is a unique network of researchers and other stakeholders dedicated to researching and preventing discrimination based on genomic and other omic data worldwide. Our overall approach is framed by recognized human rights principles including respect for autonomy, dignity, privacy, the right to science, and the right to know/right not to know.

In 2019, the GDO expanded to include a multidisciplinary team of experts and collaborators from 16 countries. In the coming year, the GDO will continue its expansion and be used as a research platform to provide a wealth of evidence for the GDO experts and collaborators to start developing harmonized policy models and education campaigns and implement them at the national and international levels (see the commentary by Joly et al. in Nature Genetics, 2020).

FOLLOW THE WORK OF OUR COLLABORATORS AROUND THE WORLD TO INVESTIGATE AND PREVENT GD

LAW

BIOETHICS

SOCIOLOGY

HEALTH POLICY

CANADA
Yann Joly | Gratien Dalpé | Charles Dupras

CANADA
Yvonne Bombard

UNITED STATES
Anyia Prince

MEXICO
Palmira Granados M.

GENETIC DISCRIMINATION

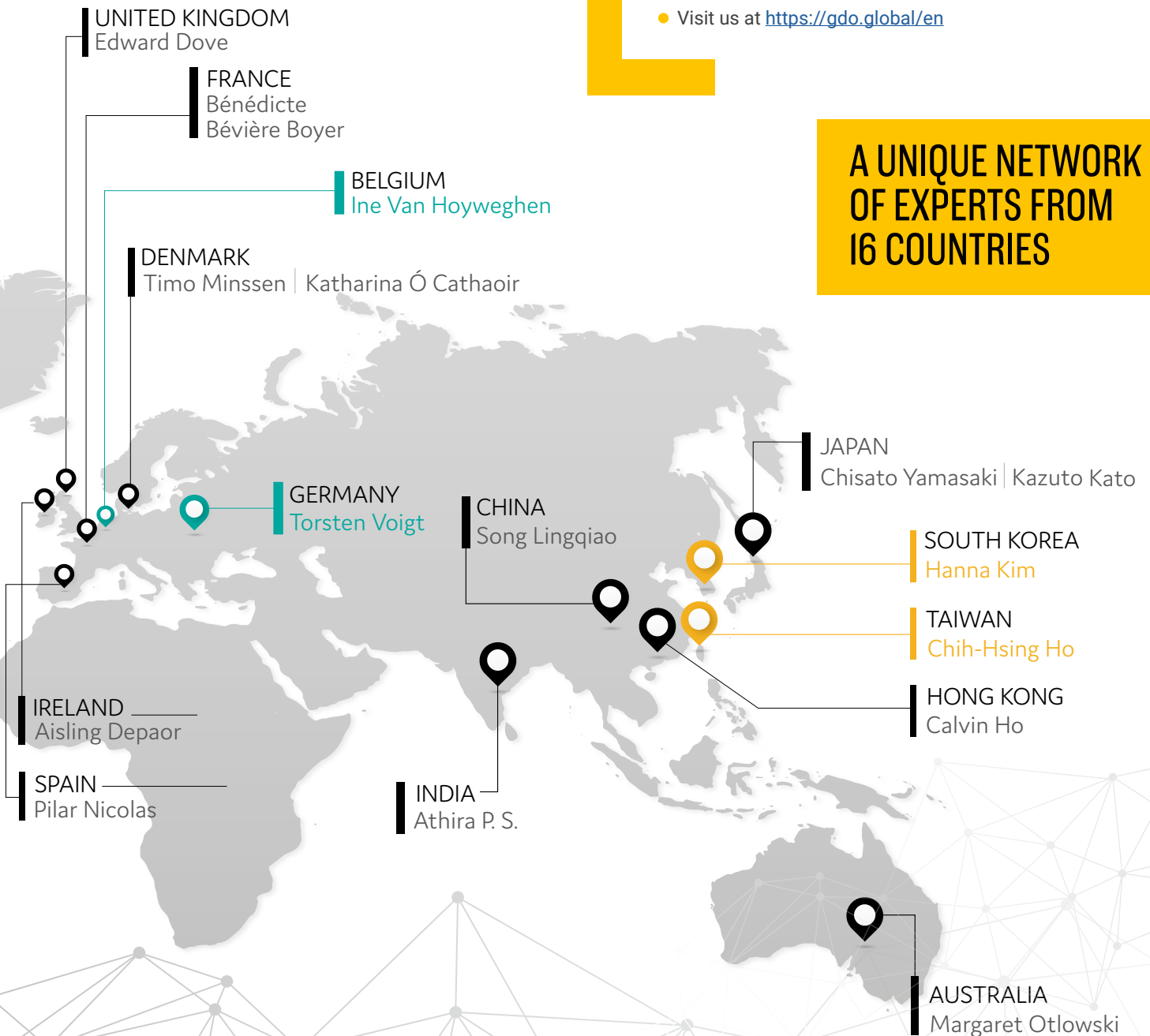


Genetic discrimination involves treating differently and negatively or unfairly profiling individuals or a group relative to the rest of the population on the basis of actual or presumed genomic and other predictive data.

The Genetic Discrimination Observatory in a nutshell:

- A team of international experts from 16 countries, a consultative committee and collaborators
- FAQs developed to provide general information about genetic discrimination
- A private report a case submission system if you have been victim of genetic discrimination
- Several maps representing the state of genetic discrimination around the world
- Resources such as tool boxes, policies and publications
- Visit us at <https://gdo.global/en>

A UNIQUE NETWORK OF EXPERTS FROM 16 COUNTRIES





P³G
becomes
P3G2

Continuing to
support policy,
ethics and
governance
frameworks in
genomic research

Over the past fifteen years, the Public Population Project in Genomics and Society ("P3G") has grown as an international consortium dedicated to facilitating collaboration between researchers and biobanks working in the area of human population genomics.

P3G was operated as a not-for-profit corporation from 2004 to 2019. As such, it was member-based and composed of experts from different disciplines in the areas of genomics – including epidemiology, law, ethics, technology, biomolecular science – committed to a philosophy of sample and data sharing with the goal of supporting researchers working in areas that will improve the health of people around the world.

Over more than a decade, P3G offered a range of services and resources to adapt to the ever-evolving needs of the research community. From the outset – when P3G first tackled the building of biobanks as resources as well as data cataloguing and harmonization for data integration – to a new mission and vision, it continually developed the tools for the conceptualization and design of population biobanks. In so doing, P3G became key in fostering research infrastructures to facilitate knowledge translation to the clinic. In particular, starting in 2014, in collaboration with the Centre of Genomics and Policy (CGP, McGill university), P3G developed the International Policy interoperability and data Access Clearinghouse (IPAC) service, offering a "one-stop" service for national and international collaborative research projects. It provided services to assist international researchers in meeting ethical and legal regulatory requirements governing genetic/genomic researcher and consortia.

Since December 2019, in consideration of the evolution and complementarity of its mandate, P3G has become P3G2, and is now a research project of the Centre of Genomics and Policy (CGP at McGill University). P3G2 continues to develop and support policy, ethics and governance frameworks for biobanking, genomic research databases and other similar health and social research infrastructure, with an aim to optimize cross-border access and use.

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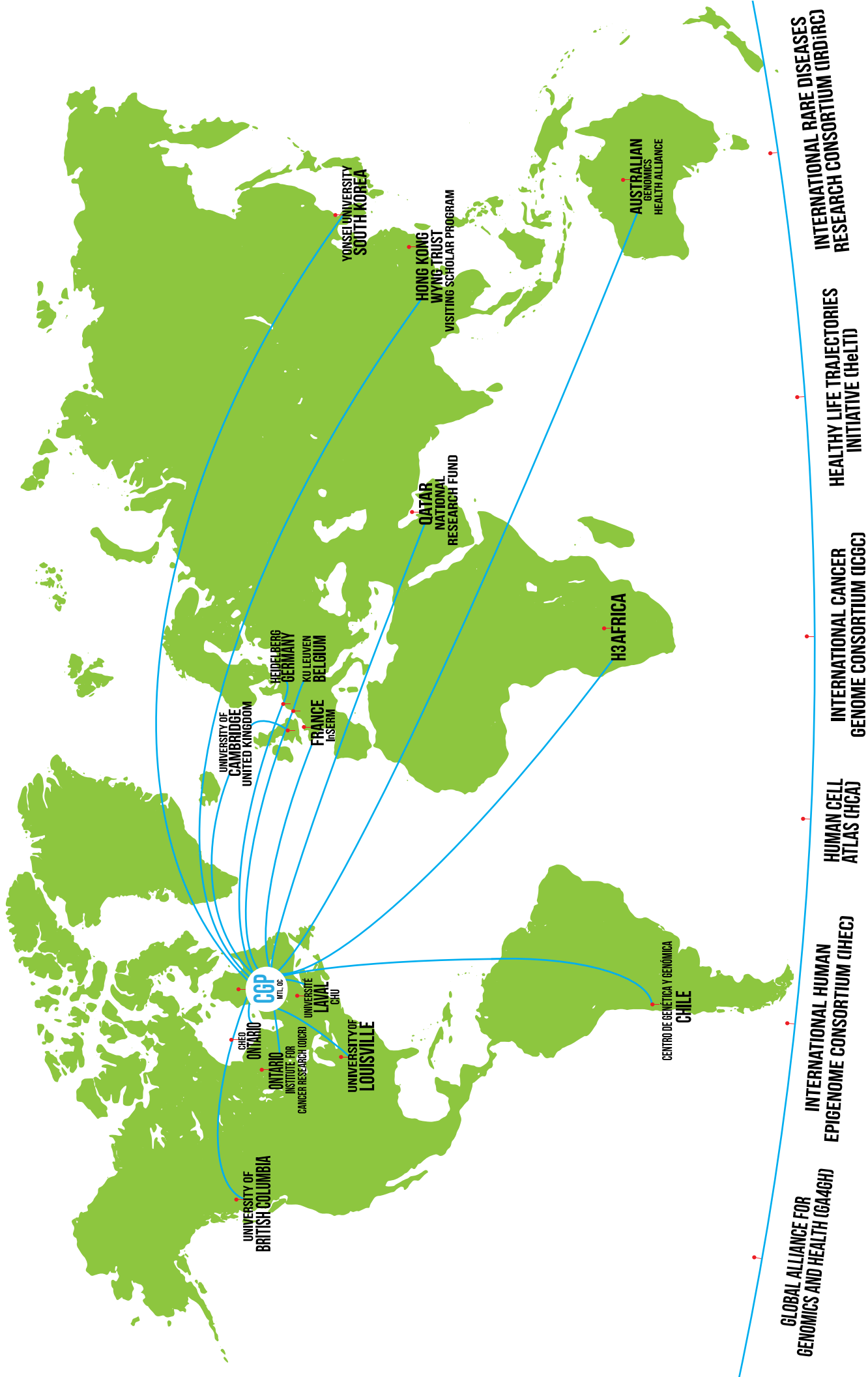
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