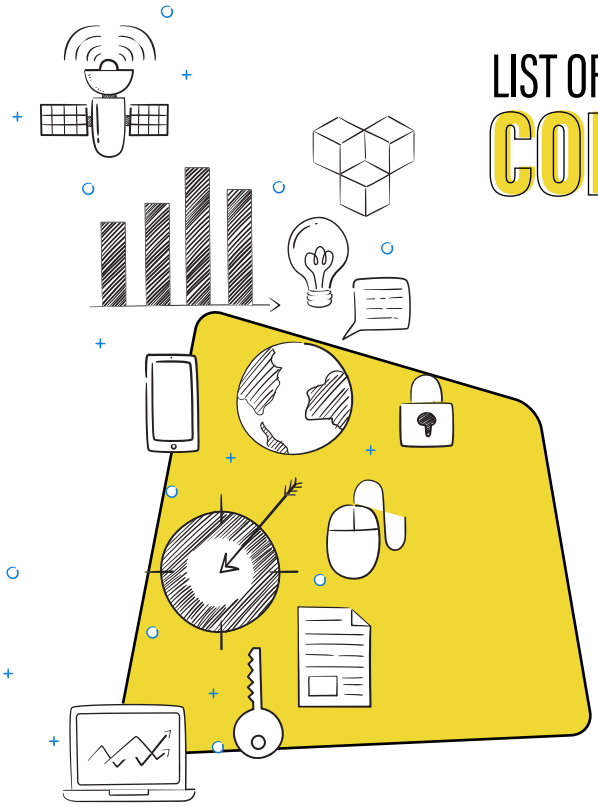
ANNUAL REPORT 2020

CGP

Centre of Genomics and Policy + Centre de génomique et politiques

https://www.genomicsandpolicy.org



LIST OF CONTENTS

Message from the DIRECTOR

PROFESSOR
Bartha Maria Knoppers

This second year began with the hope that we would all be together again, but alas, it was not to be. In spite of a few windows of hope and return to the CGP, the year was largely one "on screen".

Nevertheless, productivity was high, and several new grants were obtained. I would like to highlight the promotion of my colleague and Research Director, Yann Joly to the rank of Full Professor at the Faculty of Medicine and Health Sciences and congratulate our Executive Director, Prof. Ma'n Zawati, for being granted his Junior 1 FRQS Career Award (translational genomics and professional obligations).

Even more remarkable was our volunteer work on Canadian COVID efforts across the country and internationally. The mindset and rationale of public health, where the legal and ethical framing is necessarily in the public interest, requires moving beyond the individual and, indeed, in the case of a pandemic, beyond one's country, to the global arena. Even now, as we slowly return not only to the office but to our funded projects, we will be forever marked and cognizant of our greater responsibility as researchers, as citizens. While we at the CGP are international "comparatists" by formal training, the pandemic has made us adopt a more active human rights filter in all our work. Even a terrible pandemic has had some positive outcomes then?

Bartha Maria Knoppers

Message from the RESEARCH DIRECTOR

PROFESSOR
Yann Joly

With Quebec easing on public health measures after two years of the pandemic in March, we can see some light at the end of the tunnel! In this context, it has been inspiring to witness the resilience and optimism displayed by students and employees at the CGP during these past two years, and I wish everyone a safe and smooth transition back to McGill University. Despite the many challenges of the past year, the CGP continued to contribute significantly to many research fields, as shown by the 64 articles published by CGP members in 2021. Furthermore, we completed eight research projects this past year, with fifty more ongoing.

I'm happy to report that the CGP 2022 team continues to reflect our interest in promoting interdisciplinarity, inclusion and diversity in the workplace! The CGP welcomed four new research assistants (Robyn McDougall, Beatrice Kaiser, Aurélie Dauge and Katherine Cheung) and three interns (Dena Kia, Rim Metina-Belknap, and Natalie Keller) this year. Our research team is composed of a majority of women (78% of the group), representing over eight academic disciplines and coming from various countries that include Brazil, Canada, China, France, Mexico, Switzerland, the United States and more. The diverse composition of our team has been a key factor that has allowed us, over the years, to continually innovate with our research methodologies and pioneering projects (e.g., The Quebec SmartCare Consortium, Smartphone crowdsourced medical data for biomedical research, Regenerative Medicine Charter Update Project).

Finally, I am hopeful to be able to travel and meet my colleagues across the world at meetings of international organizations, such as the Global Alliance for Genomics and Health (GA4GH), the International Human Epigenome Consortium (IHEC) and the World Association for Medical Law (WAML).

Yann Joly

CGP

ABOUT US

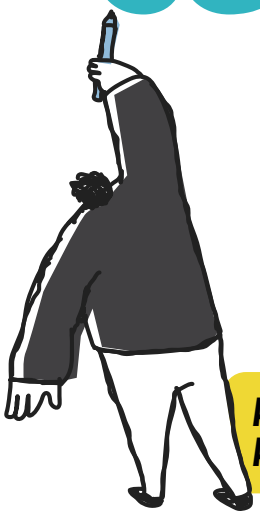
Located within the McGill Genome Centre, the Centre of Genomics and Policy (CGP) works at the crossroads of law, medicine, and public policy. Applying a multidisciplinary perspective and collaborating with national and international partners, the CGP analyzes the socio-ethical and legal norms influencing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

Currently, the CGP's research covers several areas of genomics and policy that include: stem cell research and therapies, personalized medicine, prevention and treatment of cancer, data sharing in research, pediatrics, genetic counselling, digital health and AI, intellectual property and open science, epigenetics, intersex and diversity in health, gene editing, genetic discrimination and biobanking (population genetics).

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.

See more about the Centre of Genomics and Policy.

CGP TEAM



PROFESSOR
KNOPPERS Bartha Maria - DIRECTOR

PROFESSOR
JOLY Yann - RESEARCH DIRECTOR

ASSISTANT PROFESSOR
ZAWATI Ma'n H.
EXECUTIVE DIRECTOR

ACADEMIC ASSOCIATES

BEAUVAIS Michael
BERNIER Alexander
COSQUER Marie
DALPÉ Gratien - **COORDINATOR**
DUPRAS Charles
GALLOIS Hortense
GRANADOS-MORENO Palmira
HAGAN Julie
KÉKESI-LAFRANCE Kristina
KIRBY Emily
KLEIDERMAN Erika
KNOPPERS Terese
LANG Michael
MONTEFERRANTE Erica
NGUYEN Minh Thu
PALMOUR Nicole
PATRINOS Dimitri
SONG Lingqiao
TOWLE Sarah

ASSOCIATE MEMBERS

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GOLD Richard
KIMMELMAN Jonathan

POST DOCTORAL FELLOW

DUPRAS Charles

SCIENTIFIC CONSULTANTS

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LABERGE Claude

PhD STUDENTS

NOOHI Forough
SO Derek

MASTER'S STUDENTS

BONILHA Ana
BRADBURY-JOST Jacqueline
CROCKER Kelsey
DOERKSEN Emily
HALEY Cassandra
LIU Hanshi

INVITED SCHOLARS

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ISASI Rosario
ISSA Amalia
MESLIN Eric
STOFFEL Bertrand

RESEARCH ASSISTANTS

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SHEMIE Genevieve
XU Handi

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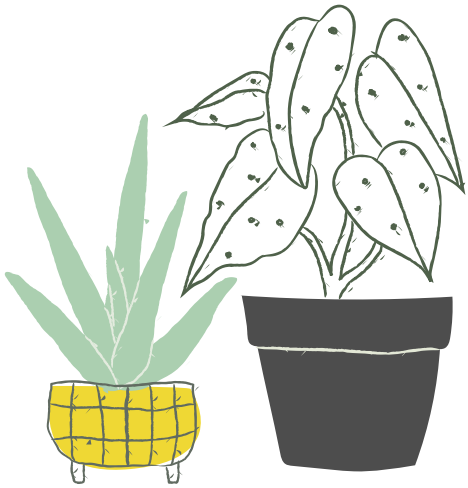
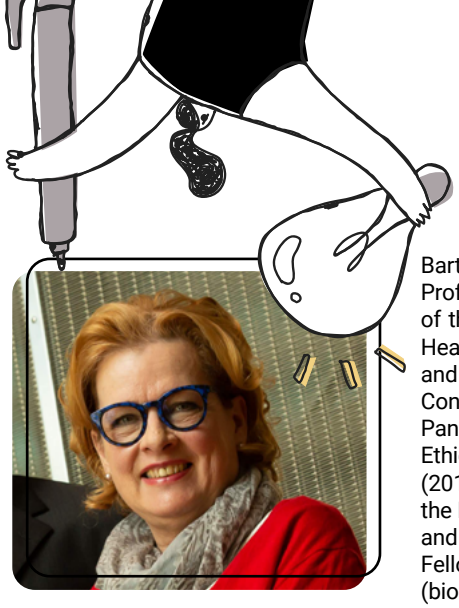
DIAS Julie-Alexia
KELLER Natalie
KIA Dena
METINA-BELKNAP Rim

ADMINISTRATORS

HOZYAN Rose-Marie
THORSEN Nadine



CGP DIRECTORS



BARTHA MARIA KNOPPERS

PROFESSOR

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 and Health Sciences at McGill University. She was the Chair of the Ethics and Governance Committee of the International Cancer Genome Consortium (2009-2017). She was the Chair of the Ethics Advisory Panel of WADA (2015-2020), and the Co-Chair of the Regulatory and Ethics Workstream of the Global Alliance for Genomics and Health (2013-2019). 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 an Officer of the Order of Canada and Quebec and was appointed to the International Commission on the Clinical Use of Human Germline Genome Editing. She was awarded the 2019 Henry G. Friesen International Prize in Health Research, the Till and McCulloch Award for science policy (2020) and the Canadian Bioethics society lifetime Achievement Award (2021).

YANN JOLY

PROFESSOR

Yann Joly, Ph.D. (DCL), FCAHS, Ad.E. is the Research Director of the Centre of Genomics and Policy (CGP). He is a Full Professor at the Faculty of Medicine and Health Sciences, 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 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).

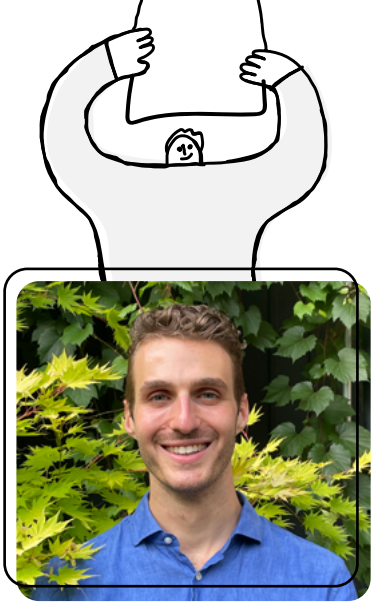
Prof. Joly's research interests lie at the interface of the fields of scientific knowledge, health law (biotechnology and other emerging health technologies) and bioethics. He created the first international genetic discrimination observatory (GDO https://gdo.global/en/gdo-description) in 2018. He has 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

ASSISTANT PROFESSOR

Ma'n H. Zawati (LL.B., LL.M., Ph.D. (DCL)) is an Assistant Professor at McGill University's Faculty of Medicine and Health Sciences and the Executive Director of the Centre of Genomics and Policy in the Department of Human Genetics. He is also an Associate Member of the Biomedical Ethics Unit and the Division of Experimental Medicine at McGill University. 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. 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 150+ international conferences, symposia, meetings, and has shared his expertise with universities, research ethics boards and law firms. Prof. Zawati has published 17 book chapters and 64+ peer reviewed articles in leading publications such as Nature Reviews Genetics, the Canadian Medical Association Journal, and the Journal of Law and the Biosciences. 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 2021, Prof. Zawati received his J1 FRQS Career Award.

ACADEMIC ASSOCIATES



MICHAEL BEAUVAIS

ACADEMIC ASSOCIATE

Michael Beauvais, BA (McGill), BA (Oxf), BCL/JD (McGill), MSc (UCL) is an academic associate at the Centre. He is currently pursuing a doctorate (SJD) at the University of Toronto's Faculty of Law. He obtained his law degrees from Oxford University and McGill University. In a former life, he studied human geography and Italian literature at McGill University and urban planning at University College London. These experiences continue to inform his perspectives on law and ethics.

At the Centre, Michael specializes in the governance of genomic, neuro, and health-related data in Canada and Europe. He is particularly interested in science policy and its relation to international human rights law. Comparative biomedical research regulation and its interface with contemporary big data research also interest him. Michael's interest in ethico-legal issues surrounding research with children and adolescents further present him with difficult practical issues with rich theoretical implications.

ALEXANDER BERNIER

ACADEMIC ASSOCIATE

Alexander Bernier is pursuing a Doctor of Juridical Science (S.J.D) at the University of Toronto, Faculty of Law, under the supervision of Professor Gillian Hadfield. His doctoral research concerns the effects of data regulation on self-assembled biomedical data commons, and law and economics perspectives on the governance and oversight thereof. Alexander obtained a Master of Laws from the University of Toronto Faculty of Law. At the Centre of Genomics and Policy, his research is primarily concerned with data protection law, open science, and research infrastructure. Alexander Bernier is a member of the European-Canadian Cancer Network's Internal Ethical Board, and is the Ethics Officer of the Canadian Open Neuroscience Platform Ethics and Data Governance Committee.

MARIE COSQUER

ACADEMIC ASSOCIATE

Marie Cosquer (M.Sc) is an Academic Associate at the Centre of Genomics and Policy (CGP) at McGill University. She obtained a Master's degree in Political Science from Université de Montréal and holds degrees in Geography and environmental projects management (B.Sc. M.Sc. Université Montpellier III, M.Sc. Université Paris VII). She is also the co-coordinator of the journal Possibles.

At the CGP, she contributes to different projects by doing qualitative research and works under the supervision of Profs. Ma'n Zawati and Yann Joly. She is currently involved in research projects about personalized therapy for individuals with cystic fibrosis and, interrogating and implementing omics for precision medicine in acute myeloid leukemia.

GRATIEN DALPÉ

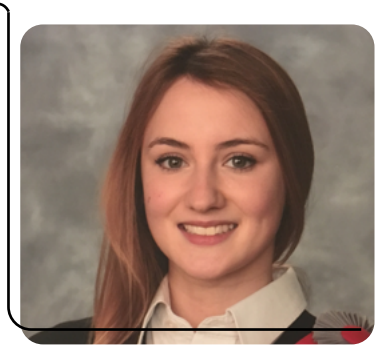
ACADEMIC ASSOCIATE
& CGP COORDINATOR

Gratien Dalpé completed his undergraduate and master studies (B.Sc/M.Sc) in biochemistry at the University of Sherbrooke. He holds a doctorate (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 that regulate the nervous system's development and degeneration. 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 with interest in law and bioethics, specifically genomic medicine and genetic discrimination. He is also the Coordinator of the Centre and a regular guest lecturer in HGEN 400 and INDS 302 at Mcgill's Faculty of Medicine and Health Sciences.

CHARLES DUPRAS

ACADEMIC ASSOCIATE

Charles Dupras, B.Sc., M.Sc., Ph.D. was a postdoctoral fellow (2017-2020) and became an academic associate at the Center of Genomics and Policy. He completed a master's degree in molecular biology at INRS-Institut Armand-Frappier, then completed a doctoral degree in bioethics at Université de Montréal. He was awarded a three-year fellowship (2017-2020) by the Canadian Institutes of Health Research (CIHR) for pursuing research on the translation of emerging knowledge in epigenetics. In particular, Charles is interested by the ethical, legal and social implications of epigenetics. He examines the impact of epigenetics on nature vs nurture representations and questions of environmental and social justice. At the Centre, Charles explores Canadian laws and public policies related to findings about epigenetic mechanisms, such as DNA methylation. The main objective is to ensure that Canadian regulations, such as the recent Genetic Non-Discrimination Act (2017) or existing guidelines for the ethical conduct of genetic research (e.g., data sharing and protection of privacy) apply consistently and justifiably to epigenetic information.



HORTENSE GALLOIS

ACADEMIC ASSOCIATE

Hortense holds a Master of Laws from the University of Lille 2 (France) and the Universidad de Murcia (Spain), specializing in new technology and health law. She obtained her Master's degree in Bioethics from the Université de Montréal in 2019. Her main interests are the ethical and legal implications of genetic and genomic research as well as the ethics of reproduction. Since 2018, she has been involved in Genome Canada's Pegasus 2 project, which studies the ethical and social acceptability of the implementation of non-invasive prenatal testing (FNITP) in Canada.

PALMIRA GRANADOS

ACADEMIC ASSOCIATE

Palmira Granados (LL.M., Ph.D. (D.C.L.) is a Mexican lawyer and Academic Associate at the Centre of Genomics and Policy of McGill University specialized in intellectual property and life sciences and bioethics. She recently obtained her PhD (Doctor of Civil Law) from the Faculty of Law at McGill University under the supervision of Professor Richard Gold.

Her work focuses on the ethical and legal aspects of research and development involving biomedicine and genomics, as well as the legal and implementation issues around open science. She has published and presented her work in international fora on the interface between intellectual property and biomedicine and information technologies, commercialization, genetic discrimination and immigration, legal issues associated with open science and open source in biomedicine and information technologies, and bioethics, to name some. She is also a guest lecturer in the graduate class of Genetics and Bioethics at McGill University and in the graduate class of Global Health Ethics at the University of Southern California, San Diego. She is currently a member of the International Expert Group of the Genetic Discrimination Observatory and the Centre for Intellectual Property and Policy of McGill University.

JULIE HAGAN

ACADEMIC ASSOCIATE

Julie (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.

KRISTINA KÉKESI-LAFRANCE

ACADEMIC ASSOCIATE

Kristina is a lawyer and LLM candidate in Bioethics at the McGill Faculty of Law. While she completed her undergraduate studies at Sherbrooke University Law Faculty, Kristina also studied abroad for a semester at the Law Faculty of Université Libre de Bruxelles. After successfully passing her bar exams, Kristina was called to the Quebec Bar in July 2018. She practiced as a lawyer in an international firm for over a year before joining the CGP.

As an Academic Associate, Kristina is interested in how law and ethics interact in the field of genomics. She is involved in different projects in both clinical and research ethics as well as international privacy laws and biobanking. In her role, Kristina is also a coordinator and policy developer of the Regulatory and Ethics Work Stream of the Global Alliance for Genomics and Health (GA4GH) and an Affiliate Graduate member of the Research Group on Health and Law at McGill.

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).

ERIKA KLEI-DERMAN

ACADEMIC ASSOCIATE

Erika Kleiderman 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 access to data and genetic information, biobanking, human genome editing, new assisted reproductive technologies, as well as the regulation of stem cell research, and cell and gene therapies. Erika is actively engaged in the stem cell and regenerative medicine community through her involvement with the Stem Cell Network's Trainee Communications and Training & Education Committees, as well as through her coordination role in the pan-Canadian initiative aimed at assessing the adequacy of existing regulatory frameworks and considerations for reframing the Assisted Human Reproduction Act, in light of evolving assisted reproductive technologies.

She was also the Coordinator of the Canadian International Data Sharing Initiative (Can-SHARE) (2015-2019) and the Access Officer of the Canadian Partnership for Tomorrow Project (CPTP) (2018-2019), for which she was actively involved in the development of controlled data and biosample access documentation and operating procedures. Erika is also interested in the potential applications of gene editing for performance enhancement (gene doping), as well as the implications of gene therapy and enhancement in minors within a sporting context.

She is a member of CIHR's Stem Cell Oversight Committee and the McGill University Health Centre Research Ethics Board.

TERESE KNOPPERS

ACADEMIC ASSOCIATE

Terese holds a Bachelor of Arts in Sociology from McGill University and a Master of Arts in Counselling Psychology from Simon Fraser University. They have a background in qualitative methods and equity, diversity, and inclusion (EDI) research. They are particularly interested in research that helps improve healthcare access and provision.

At the CGP, Terese helps to coordinate a variety of qualitative projects. They are presently involved in projects on the improvement of healthcare communication practices with intersex people, perspectives of cystic fibrosis patients and caregivers on biomedical research, impacts of the lack of legal recognition of genetic counsellors in Quebec and ethical, legal and social implications of epigenetics.

MICHAEL LANG

ACADEMIC ASSOCIATE

Michael is a lawyer and member of the Law Society of Ontario. He graduated from the McGill Faculty of Law's joint BCL/LLB program with honours in 2018. He is an LLM candidate in McGill's Faculty of Law, where he is preparing a thesis on artificially intelligent decision-making in medicine and the right to explanation. He has an undergraduate degree in philosophy from the University of Alberta. Michael's research broadly addresses 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.

ERICA MONTE-FERRANTE

ACADEMIC ASSOCIATE

Erica is an academic associate of the Centre of Genomics and Policy at McGill University. She holds degrees from Université de Montréal (MA, Bioethics) and McGill University (BA, Western Religions). Her graduate research explored the concept of moral distress, as it relates to decision-making. Erica's other areas of focus include moral deliberation, research ethics, artificial intelligence, and the ethical, legal, and policy implications of health research and health governance.

She joins Prof. Ma'n Zawati's team on projects involving (1) responsible biobanking policies and (2) health policy guidelines for smartphone applications.

MINH THU NGUYEN

ACADEMIC ASSOCIATE

Minh Thu Nguyen 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.

Nicole Palmour is an academic associate at the Centre of Genomics and Policy at McGill University, with a background in biology, psychology (BA), forensic psychology (MA), and human genetics with a bioethics specialization (PhD). Her research interests are situated at the interface of the fields of bioethics, scientific knowledge, neurodiversity and health law.

NICOLE PALMOUR

ACADEMIC ASSOCIATE

DIMITRI PATRINOS

ACADEMIC ASSOCIATE

Dimitri is a lawyer and an Academic Associate at the Centre of Genomics and Policy (CGP) at McGill University. He is currently pursuing his Master of Laws (LL.M.) degree at McGill University's Faculty of Law and is a graduate fellow of the McGill Research Group on Health and Law. He is a graduate of the civil law (LL.B.) and common law (J.D.) programs at Université de Montréal, Faculty of Law. He also holds a B.Sc. in Biology from Concordia University. He was called to the Ontario Bar in 2020 and is a jurist member of the McGill University Health Centre (MUHC) Research Ethics Board.

LINGQIAO SONG

ACADEMIC ASSOCIATE

Ms. Lingqiao Song acquired a B.Sc in Biology and a Master's Degree of Civil Law at the Chinese Academy of Social Science in China. In 2015, she completed her second Master's degree of international business law at University of Montreal and was awarded the "Dean's Award: Best Overall Academic Achievement". In 2016, she was admitted as Chinese Lawyer and worked as a legal consultant for Anran Law firm in China. She is also a member of the Institutional Review Board at the Faculty of Medicine and Health Sciences, 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, misusage 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.

SARAH TOWLE

ACADEMIC ASSOCIATE

Sarah Towle is an Academic Associate at the Centre of Genomics and Policy. She holds a Master of Science in Family Medicine and Bioethics from McGill University, focusing on feminist and intersectional approaches to healthcare. While pursuing studies at McGill, Sarah worked as an equity workshop facilitator in the Faculty of Medicine and led the university's first-ever support and advocacy group for First-Generation students and academics.

Her main research interests include patient representation and direct-to-consumer genetic testing. At the Centre, Sarah works under the direction of Ma'n Zawati on projects related to COVID-19, biobanking, and mobile-health apps.

INVITED SCHOLAR

BERTRAND STOFFEL

INVITED SCHOLAR

As a legal policy scholar, Bertrand Stoffel studies the legal and socio-ethical dimensions of human enhancement, as well as the regulation of drugs in society. At the intersection of law, criminal justice, and health policy, his research focuses among other things on rule breakers' decision-making process and regulatory strategies to complement deterrence-based interventions.

Bertrand Stoffel was a Postdoctoral Fellow at McGill's Institute for Health and Social Policy, holds a Doctorate of Law from the University of Zurich, Switzerland (2017), and is a member of the Bar of Zurich (2016). He is an editor for the Canadian Journal of Bioethics.

PH.D. STUDENTS

FOROUGH NOOHI

Ph.D. 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 "threeparent 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.

DEREK SO

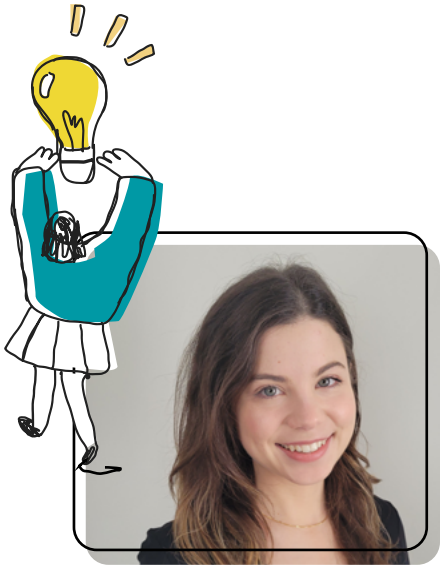
Ph.D. STUDENT

"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

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.

MASTER'S STUDENTS



"Clinical use of Genome Wide Sequencing and Polygenic Risk Scores: Ethical Considerations for Genetic Counsellors"

Supervisor: Ma'n H. Zawati, Centre of Genomics and Policy, McGill University

ANA ELIZA BONILHA

MASTER'S STUDENT

Ana Eliza is currently pursuing a Master of Science in Human Genetics with a concentration in Bioethics, under the supervision of Prof. Ma'n Zawati. She also holds a bachelor's degree in Biomedical Sciences from McGill University. At the CGP, Ana is involved in different projects such as the International Cancer Genome Consortium (ICGC), the MSSNG Autism Speaks and the Canadian COVID-19 Genomics Network (CanCOGeN).

JACQUELINE BRADBURY -JOST

MASTER'S STUDENT

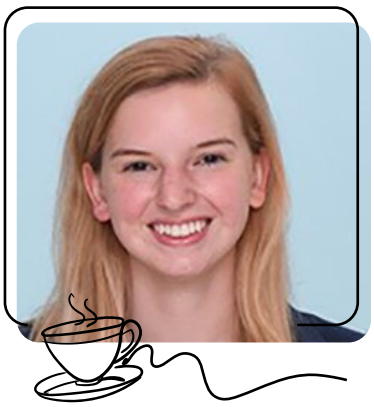
"Return of Material Incidental Findings to Participants in the Context of Research Conducted by Direct-to-Consumer Genetic Testing Companies"

Supervisor: Ma'n H. Zawati, Centre of Genomics and Policy, McGill University

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

Jacqueline is a Master of Science student in the Department of Human Genetics at McGill University under the supervision of Prof. Ma'n Zawati. She is also pursuing a Master's Specialization in Bioethics through McGill's Biomedical Ethics Unit. Prior to beginning her studies at McGill, Jacqueline completed undergraduate studies in humanities and biology with particular interests in philosophy, political science, and genetics. In her fourth year, she undertook directed studies projects in genetics, with a focus on anti-angiogenesis cancer therapy, as well as in philosophy, looking at moral agency in Spinoza's Ethics. She received a Bachelor of Humanities and Biology (Combined Honours) with High Distinction from Carleton University in 2019.

Jacqueline's research at the Centre of Genomics and Policy focuses on the ethical and legal implications of novel health technologies and is funded by a CIHR Master's award.



"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 CROCKER

MASTER'S STUDENT

Kelsey is a Master of Science student in the Department of Human Genetics at McGill University and the Centre of Genomics and Policy 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 Attachment Programme in Science (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 gene editing and genetic enhancement in a healthcare context.

MASTER'S STUDENTS

EMILY DOERKSEN

MASTER'S STUDENT

"Public Perception and Biobank Ethics Governance During Pandemics"

Supervisor: Ma'n H. Zawati, Centre of Genomics and Policy, McGill University

Emily is currently pursuing a Master of Science at the Department of Human Genetics and the Biomedical Ethics Unit at McGill University. She holds a Bachelor of Humanities with a combined Honours in Biology from Carleton University, a B.A. in Philosophy from KU Leuven (Belgium), and an M.A. in Philosophy from the University of Ottawa. Her undergraduate and graduate educations inform her interdisciplinary interests in public health and bioethical issues relating to human genetics and research ethics governance.

At the CGP, Emily is working under the supervision of Prof. Ma'n Zawati, researching the internal governance policies of Canadian COVID-19 Biobanks.

CASSANDRA HALEY

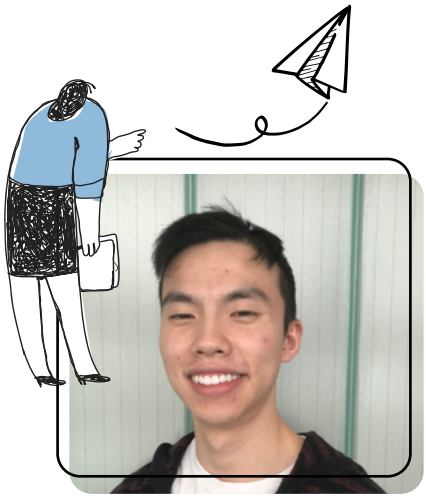
MASTER'S STUDENT

"Direct-to-consumer genetic tests: Is there a role for Canadian genetic counsellors?"

Supervisor: Ma'n H. Zawati, Centre of Genomics and Policy, McGill University

Cassandra Haley is a Master of Science student from the Department of Experimental Medicine and the Biomedical Ethics Unit at McGill University under the supervision of Prof. Zawati. She holds a Bachelor of Science from the University of Western Ontario, where she pursued an honours specialization in genetics and a major from the School for Advanced Studies in the Arts and Humanities. Cassandra's undergraduate thesis was on the genotoxicity of microplastics, and through her humanities courses she worked closely with local Indigenous communities to research the Indigenous experience of WWI. Cassandra has also written extensively on the sociological and cultural history of music for an internship through the Faculty of Music.

This interdisciplinary background motivated Cassandra to pursue genetics and bioethics at the graduate level, where she will be researching how Canadian genetic counsellors can respond to the rise of direct-to-consumer genetic tests.



HANSHI LIU

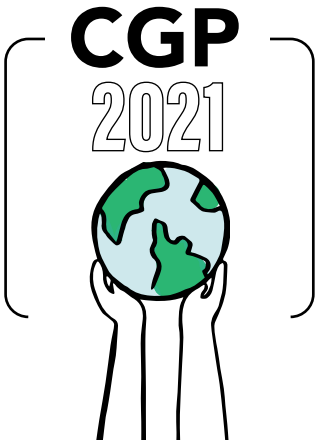
MASTER'S STUDENT

"Exploring the legal, ethical and social challenges of collecting ethnic/racial contextual data in COVID-19 case reports"

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

Hanshi is pursuing a master's degree in Human Genetics with a concentration in Bioethics, being supervised by Professor Yann Joly. He is interested in new legal and ethical challenges raised by the development of recent medical and scientific advances in the fields of Health. At the CGP, his primary research focuses on data sharing in the omic sciences, and the privacy/ethical issues associated with it. Hanshi has been involved in numerous projects at the Centre from the Canadian COVID Genomics Consortium (CanCOGeN), D-PATH, to various Data Access Committees.

INVOLVEMENT IN THE FIGHT AGAINST COVID-19



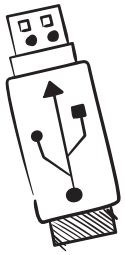
In 2021, the CGP took part in national and international efforts to respond to the current COVID-19 pandemic.The CGP has contributed its expertise in data governance, data sharing and privacy for the following collaborative COVID initiatives:

NATIONAL COVID-19 VACCINE TASK FORCE

Bartha Knoppers: Member

CANADIAN COVID-19 HUMAN HOST GENOME SEQUENCING PROGRAM (CGEN)

Bartha Knoppers: Member, Steering Committee



PROACTIVE MITIGATION PROGRAMME, LUXEMBOURG CENTRE FOR SYSTEMS BIOMEDICINE, UNIVERSITY OF LUXEMBOURG

Bartha Knoppers: Member, Strategic Advisory Board

CanCOGen
CANADIAN COVID-19 GENOMICS NETWORK

Bartha Knoppers: Member, COVID-19 Host Genetics Initiative (HostSeq) Implementation Committee

Yann Joly: Chair, Data Sharing Committee
Ethics and Governance Committee
Member, Management Committee
(SARS-CoV-2 Data Portal, VirusSeq)
Principal Investigator:
ELSI COMPONENT: VIRUSSEQ (CanCOGeN), Research project funded by Genome Canada

Ma'n H. Zawati: Member, Data Sharing Committee
Member, Coordination Committee
Principal Investigator:
ETHICS AND POLICY PILLAR – HostSeq (CanCOGeN), research project funded by Genome Canada

GA4GH
GENOMIC DATA SHARING TOOLS AGAINST COVID-19 FUNDING OPPORTUNITY

Yann Joly (Collaborator): Research project funded by the Canadian Institutes of Health Research (CIHR)

QUÉBEC BIOBANK ON COVID-19

Yann Joly: Member, Task Force

Ma'n H. Zawati: Member, Steering Committee

ETHICAL LEGAL EXPERTISE – COVID-19 IMMUNITY TASK FORCE (CITF)

Ma'n H. Zawati (Principal Investigator): Research project funded by the Public Health Agency of Canada

COVID-19 CLOUD

Ma'n H. Zawati (Co-Investigator): Digital Technology Supercluster – Government of Canada

OF BIOBANKING AND POLICY: EMERGING ETHICAL AND LEGAL CHALLENGES DURING THE COVID-19 PANDEMIC

Ma'n H. Zawati (Principal Investigator): Research project funded by Social Sciences and Humanitites Research Coucil of Canada (SSHRC), MI4 Emergency COVID-19 Research Funding (ECRF)

COMPLETED PROJECTS

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

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

JANUARY 2018 – DECEMBER 2021
HEALTHY LIFE TRAJECTORIES (HELTI): GOVERNANCE FRAMEWORK

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

JUNE 2020 – OCTOBER 2021
CANADIAN OPEN NEUROSCIENCE PLATFORM (CONP) – ETHICS AND GOVERNANCE COMMITTEE; SCHOLARSHIP SUPERVISION

MAY 2019 – APRIL 2021
CopaQ: INITIATIVE DE SCIENCE PARTICIPATIVE EN RECHERCHE SUR LES POPULATIONS

JANUARY 2020 – DECEMBER 2021
THE INTERNATIONAL CANCER GENOME CONSORTIUM (ICGC) DATA ACCESS COMPLIANCE OFFICE (DACO)

JUNE 2020 – DECEMBER 2021
COVID-19 CLOUD

APRIL 2016 MARCH 2021

RESEARCH ADVANCEMENT THROUGH COHORT CATALOGUING AND HARMONIZATION (REACH)

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 the 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 cohort data and biological samples. The CGP's role is to study 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 will compare the different clauses and processes to identify similarities and divergences and has notably developed a Points-to-Consider document 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.

PRINCIPAL INVESTIGATOR
FORTIER Isabel

CO-INVESTIGATORS
ATKINSON Stephanie
BOCKING Alan
FERRETTI Vincent
FRASER William
KNOPPERS Bartha Maria

ACADEMIC ASSOCIATE
BERNIER Alexander

INTERN
KELLER Natalie

APRIL 2016 MARCH 2021

CANDIG: CANADIAN DISTRIBUTED CYBER-INFRASTRUCTURE FOR GENOMICS

Canadian Institutes of Health Research (CIHR)

The Distributed Infrastructure for Genomics Data Sharing and Analysis project is divided into four activities. In Activity 1, the CGP developed a broad Canadian data sharing framework, using the APIs developed under the auspices of the Global Alliance for Genomics and Health (GA4GH). Activity 2 continued 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 built 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 to enable genome-guided clinical trials across Canada. Finally, Activity 4 established the Canadian Molecular Profiling in Cancer Trials (CAMPACT) Interchange. Together, the four activities utilized Compute Canada infrastructure to build a distributed and secure computational framework for the analysis of genomic datasets relevant to human diseases and beyond. The CGP also contributed 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.

PRINCIPAL INVESTIGATOR
BRUDNO Michael

RESEARCH COLLABORATORS
BASIK Mark
BOURQUE Guillaume
JACQUES Pierre-Étienne
JOLY Yann
JONES Steven
PUGH Trevor
VIRTANEN Carl

ACADEMIC ASSOCIATE
GRANADOS-MORENO Palmira

RESEARCH ASSISTANT
LIU Hanshi

JANUARY 2018 DECEMBER 2021

HEALTHY LIFE TRAJECTORIES (HELTI): GOVERNANCE FRAMEWORK

Canadian Institutes of Health Research (CIHR)

The HeLTI program was developed by the Institute of Human Development (Child and Youth Health) under the Canadian Institutes of Health Research (CIHR). The program represented a partnership between CIHR, the South African Medical Research Council, India's Department of Biotechnology, 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 commenced in Soweto (South Africa), Mysore (India), Shanghai (China), and across Canada. All projects focused towards developing evidence based interventions that spanned from pre-conception across pregnancy and into the postnatal period with a goal of improving maternal, infant and child health. The CGP was involved in the development of governance tools to foster international data sharing.

PRINCIPAL INVESTIGATORS
LYE Stephen
MATTHEWS Stephen

CO-INVESTIGATOR
ZAWATI Ma'n H.

ACADEMIC ASSOCIATE
PATRINOS Dimitri

OCTOBER 2018
SEPTEMBER 2021

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

Qatar National Research Fund

Genomic medicine and personalized healthcare are becoming increasingly prevalent in the Gulf region, raising difficult ethical and policy questions for the public and regulators alike. As healthcare systems increasingly emphasize these emerging fields, the public will be exposed both to the science of genomic medicine and to associated issues in Islamic ethics. There has been little scholarly or public debate on the implications of genetics on Islamic ethics. This project attempts to address these gaps by developing 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. The team at the CGP has performed a comparative analysis of international genomics norms that will serve as a grounding to inform genomics and personalized medicine policy development in the Gulf region. The project aimed to present concrete proposals for addressing key ethical issues in the field of genomics, including privacy, consent, the return of results, sensitive data management, communication of incidental findings, and data sharing.

PRINCIPAL INVESTIGATOR
GHALY Mohammed

CO-INVESTIGATOR
ZAWATI Ma'n H.

ACADEMIC ASSOCIATE
LANG Michael

JUNE 2020
OCTOBER 2021

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

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, translational, 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 Prof. Bartha Maria Knoppers and managed by Michael Beauvais. The Committee has generated an Ethics and Data Governance Framework, as well as Publication and Commercialization Policies to promote responsible open neuroscience and a Portal privacy policy to ensure the responsible use of portal users' data by CONP. The Committee's Open-Science consent clauses and retrospective filter are soon to be completed, with authentication policies and other novel outputs in the pipeline.

PRINCIPAL INVESTIGATOR
EVANS Alan

CO-INVESTIGATOR
KNOPPERS Bartha Maria

ACADEMIC ASSOCIATES
BEAUVAIS Michael
BERNIER Alexander

MAY 2019
APRIL 2021

COPAQ : INITIATIVE DE SCIENCE PARTICIPATIVE EN RECHERCHE SUR LES POPULATIONS

Fonds de la recherche en santé du Québec (FRSQ)

In recent years, genetic testing available to consumers online through private companies, also known as direct-to-consumer (DTC) genetic testing, has increased significantly. A growing number of individuals now have access to information about their genome, which represents a person's complete set of genes. With this information, people are able to discover information about their ancestors, genealogical links with other people and, in some cases, genetic risk factors.

DTC genetic testing has enabled the assembly of large cohorts, which represent a group of people that can provide valuable information for scientific research. However, this information remains mostly under the control of private companies, limiting opportunities for research.

The objective of CopaQ was to develop a platform for the collection, sharing, and simplified interpretation of population research results. This platform collected genetic, genealogic and basic demographic information from individuals who had already performed a genetic test with a private company (e.g. 23andMe, Ancestry, etc.) in order to securely share this information with members of the research community that agreed to protect its confidential nature. The CGP developed the consent form for this project and also advised on ethical and legal issues.

PRINCIPAL INVESTIGATOR
GIRARD Simon

CO-INVESTIGATORS
GRAVEL Simon
JOLY Yann
VÉZINA Hélène

COLLABORATOR
ZAWATI Ma'n H.

ACADEMIC ASSOCIATES
GALLOIS Hortense
PATRINOS Dimitri

JANUARY 2020
DECEMBER 2021

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

University of Glasgow

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 culminatory 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 managed the data access process in order to ensure that cutting edge cancer research progressed 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
BIANKIN Andrew

CO-INVESTIGATOR
ZAWATI Ma'n H.

ACADEMIC ASSOCIATES
BERNIER Alexander
LANG Michael

MASTER'S STUDENTS
BONILHA Ana Eliza
CROCKER Kelsey
LIU Hanshi

JUNE 2020
DECEMBER 2021

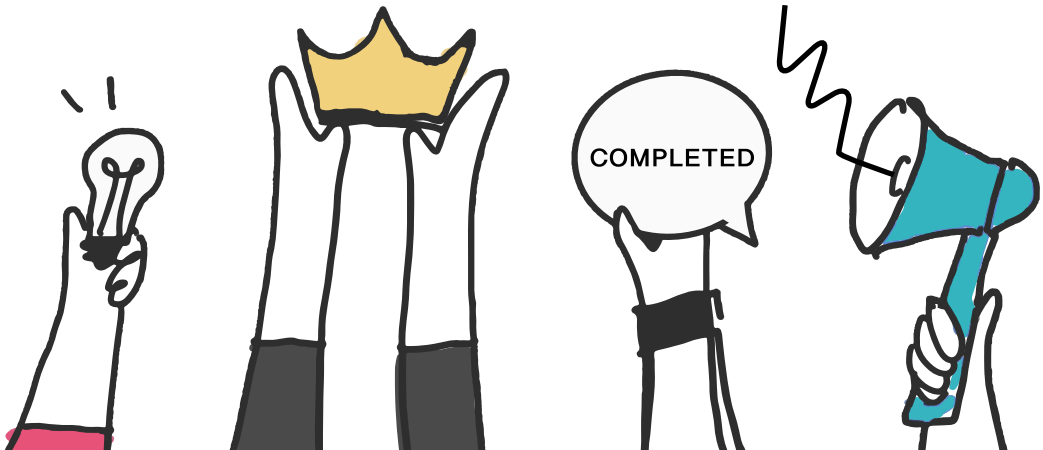
COVID-19 CLOUD

Digital Technology Supercluster – Government of Canada

As COVID-19 continues to spread globally, there is an urgent need to understand the DNA footprint of this rapidly evolving virus. Led by DNAstack, the COVID Cloud Project harnesses Canada's genomic research capabilities to rapidly sequence, share and analyze the genomic profile of COVID-19 and the people who have contracted it in Canada and around the world. This information will help inform the development of public health policies, diagnostics, therapies and vaccines. The CGP team mapped relevant provincial, federal, and international data privacy laws and research ethics regulations and worked to determine how their application is affected in emergency situations. The team further worked to design a streamlined access model based on the international GA4GH research passport standard, allowing credentialed researchers to access data and search networks for specific purposes, including COVID-19 research.

PRINCIPAL INVESTIGATOR
FIUME Mark

CO-INVESTIGATOR
ZAWATI Ma'n H.



ONGOING PROJECTS

APRIL 2009 MARCH 2022
ThéCell : RÉSEAU DE THÉRAPIE CELLULAIRE, TISSULAIRE ET GÉNIQUE DU QUÉBEC

APRIL 2016 MARCH 2022
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 JUNE 2022
THE GENDER SPECIFIC EFFECTS OF PRENATAL ADVERSITY ON THE DEVELOPMENT OF ANXIOUS AND DEPRESSIVE PSYCHOPATHOLOGY IN EARLY ADOLESCENCE

APRIL 2016 MARCH 2024
Sino-Canada HeLTI: A MULTIFACETED COMMUNITY-FAMILY- MOTHERCHILD INTERVENTION STUDY FOR THE PREVENTION OF CHILDHOOD OBESITY (SCHeLTI)

FEBRUARY 2017 JANUARY 2024
MULTIDIMENSIONAL EPIGENOMICS MAPPING CENTRE (EMC) AT MCGILL

MARCH 2018 JANUARY 2022
REGULATION OF INTERNATIONAL DIRECT-TO-PARTICIPANT (DTP) GENOMIC RESEARCH

MARCH 2018 MARCH 2023
TOWARD EFFECTIVE HEALTH COMMUNICATION WITH INTERSEX CANADIANS: A STUDY OF ETHICAL AND LEGAL CHALLENGES

APRIL 2018 MARCH 2022
QUEBEC 1000 FAMILIES (Q1K) PROJECT (TRANSFORMING AUTISM CARE CONSORTIUM)

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 – MARCH 2022
MCGILL UNIVERSITY AND GÉNOME QUÉBEC INNOVATION CENTRE

APRIL 2018 – MARCH 2023
PRECISION ONCOLOGY FOR YOUNG PEOPLE (PROFYLE 2)

APRIL 2018 – MARCH 2023
CARE4RARE CANADA: HARNESSING MULTI-OMICS TO DELIVER INNOVATIVE DIAGNOSTIC CARE FOR RARE GENETIC DISEASES IN CANADA (C4R-SOLVE)

APRIL 2018 – MARCH 2023
INTERROGATING AND IMPLEMENTING OMICS FOR PRECISION MEDICINE IN ACUTE MYELOID LEUKEMIA

JULY 2018 – JUNE 2025
MSSNG DATABASE – DATA ACCESS COMPLIANCE OFFICE

OCTOBER 2018 – SEPTEMBER 2022
EPIGENOMICS SECURE DATA SHARING PLATFORM FOR INTEGRATIVE ANALYSES (EPISHARE)

OCTOBER 2018 – SEPTEMBER 2025
EUCANSHARE: AN EU-CANADA JOINT INFRASTRUCTURE FOR NEXT-GENERATION MULTI-STUDY HEART RESEARCH

NOVEMBER 2018 – OCTOBER 2023
HUMAN CELL ATLAS: ETHICS AND GOVERNANCE

JANUARY 2019 – DECEMBER 2023
CAN-SHARE CONNECT: SUPPORTING THE REGULATORY AND ETHICS WORK STREAM OF THE GLOBAL ALLIANCE FOR GENOMICS AND HEALTH (GA4GH)

APRIL 2019 – MARCH 2022
CANADIAN GENOMICS PARTNERSHIP FOR RARE DISEASE (CGP4-RD): POLICY TOOLKIT

APRIL 2019 – MARCH 2022
CANADIAN PARTNERSHIP FOR TOMORROW'S HEALTH (CanPath)

APRIL 2019 – SEPTEMBER 2022
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
LE CONSORTIUM QUÉBÉCOIS CONTRE LE CANCER POUR DE NOUVEAUX AGENTS THÉRAPEUTIQUES ET BIOMARQUEURS

APRIL 2019 MARCH 2023

THE CANCER GENOME COLLABORATORY

OCTOBER 2019 AUGUST 2022

THE McGILL CLINICAL GENOMICS (McG) PROGRAM

JANUARY 2020 JANUARY 2023

ETHICAL AND LEGAL FRAMEWORK FOR DIRECT-TO-PARTICIPANT (DTP) RECRUITMENT

JANUARY 2020 JANUARY 2023

SELF-ASSEMBLY SKIN SUBSTITUTES (SASS) FOR THE TREATMENT OF ACUTE WOUNDS OF CANADIAN BURN PATIENTS

JANUARY 2020 JANUARY 2023

CULTURED EPITHELIAL CORNEAL AUTOGRAFTS FOR THE TREATMENT OF CANADIANS WITH LIMBAL STEM CELL DEFICIENCY

JANUARY 2020 JULY 2023

THE QGPRS STUDY: QATAR GENOME POLYGENIC RISK SCORE, A PRECISION MEDICINE APPROACH TO PREVENT DIABETIC COMPLICATIONS IN THE AFFECTED QATARI INDIVIDUALS

MARCH 2020 SEPTEMBER 2022

AUTISM SHARING INITIATIVE

APRIL 2020 MARCH 2022

OPPORTUNITIES AND CHALLENGES OF USING EPIGENETIC TECHNOLOGIES IN DEFENCE AND SECURITY CONTEXTS

APRIL 2020 JANUARY 2023

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

APRIL 2020 MARCH 2023

DOvEEgene

APRIL 2020 APRIL 2023

UN NANO-VACCIN CONTRE LES MALADIES CARDIOVASCULAIRES (AUDACE)

MAY 2020 APRIL 2022

OF BIOBANKING AND POLICY: EMERGING ETHICAL AND LEGAL CHALLENGES DURING THE COVID-19 PANDEMIC

MAY 2020 MARCH 2022

ELSI COMPONENT: VIRUSSEQ—CANCOGEN

JUNE 2020 MAY 2022

ETHICS AND POLICY PILLAR-HostSeq (CanCOGeN)

JULY 2020 MARCH 2023

ETHICAL LEGAL EXPERTISE – COVID-19 IMMUNITY TASK FORCE (CITF)

SEPTEMBER 2020 OCTOBER 2022

INNOVE-ONCO – TECHNOLOGICAL AND ORGANIZATIONAL INNOVATIONS GO HAND IN HAND: A COLLABORATIVE MODEL TO RENDER ONCOGENETICS MORE FLEXIBLE, ACCESSIBLE AND EFFICIENT

SEPTEMBER 2020 JANUARY 2023

TOWARDS AN EPIDERMOLYSIS BULLOSA CLINICAL TRIAL WITH TISSUE-ENGINEERED SKIN AFTER EX VIVO GENE THERAPY CORRECTION

NOVEMBER 2020 MARCH 2022

SECUREDATA4HEALTH

NOVEMBER 2020 DECEMBER 2022

DEVELOPPEMENT D'UN CADRE ETHIQUE ET LEGAL POUR LE DEPLOIEMENT DES ACTIVITES DU RQDM ET L'HARMONISATION DU CONSENTEMENT DES PATIENTS / DEVELOPMENT OF AN ETHICAL AND LEGAL FRAMEWORK FOR THE DEPLOYMENT OF RQDM ACTIVITIES AND THE HARMONIZATION OF PATIENT CONSENT

JANUARY 2021 DECEMBER 2023

SMARTPHONE CROWDSOURCED MEDICAL DATA FOR BIOMEDICAL RESEARCH: ADDRESSING THE ETHICAL, LEGAL AND HEALTH POLICY CONCERNS

JANUARY 2021 JUNE 2024

THE QUEBEC SMARTCARE CONSORTIUM

APRIL 2021 MARCH 2022

REGENERATIVE MEDICINE CHARTER UPDATE PROJECT

JULY 2021 JULY 2022

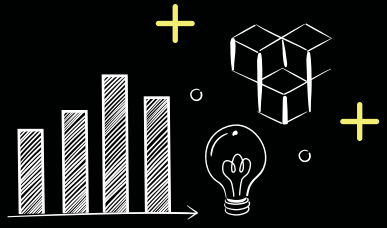
GA4GH GENOMIC DATA SHARING TOOLS AGAINST COVID-19 FUNDING OPPORTUNITY

JULY 2021 JULY 2025

A CGMP FACILITY FOR PERSONALIZED TISSUE ENGINEERING

AUGUST 2021 MARCH 2022

COMPARATIVE REVIEW OF HEALTH DATA SHARING IN CANADA - PHAC



APRIL 2009 MARCH 2022

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

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 Québec 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 reflections 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) and 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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APRIL 2016 MARCH 2022

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

Canadian Institutes of Health Research (CIHR)

The advanced 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 United Kingdom, 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, and 2) addressing issues of consent and the need to re-contact child participants once they become adults.

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APRIL 2016 JUNE 2022

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

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: 1) the safeguarding of pediatric genomic data; and 2) the consent for data use from children as they become adults.

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APRIL 2016 MARCH 2024

SINO-CANADA HELTI: A MULTIFACETED COMMUNITY-FAMILY-MOTHERCHILD INTERVENTION STUDY FOR THE PREVENTION OF CHILDHOOD OBESITY (SCHELTI)

Canadian Institutes of Health Research (CIHR)

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 large birth cohort studies, clinical trials and studies on the development of metabolic disorders, our transdisciplinary Chinese-Canadian team will conduct a multi-site and community-based randomized controlled trial. This trial will test the effect of a family-mother-child intervention package (incorporated into routine patient care) on childhood OWO rates in children aged one through six. 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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MULTIDIMENSIONAL EPIGENOMICS MAPPING CENTRE (EMC) AT MCGILL

Canadian Institutes of Health Research (CIHR)

To join global efforts, the International Human Epigenome Consortium (IHEC) has established an Epigenome Mapping Centre (EMC) at McGill University which employs epigenome mapping to understand interactions between environment and genome in human blood cells, to interpret diseases impacting metabolism using tissue samples, and to study how epigenetic changes can alter function of the brain. The large-scale generation and sharing of human epigenome data presents challenges to the process of informed consent which 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 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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MARCH 2018
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REGULATION OF INTERNATIONAL DIRECT-TO-PARTICIPANT (DTP) GENOMIC RESEARCH

National Institutes of Health (NIH)

This study aims to understand and document the regulation of Direct-To-Participant (DTP) genomic research around the world. We developed and distributed a survey to law and policy experts in 31 countries in order to clarify the law, regulation, and policy governing this novel and emerging approach to research recruitment in the genomics context. Our team at the CGP played a central role in research design, participated in expert working groups to identify and prioritize the key issues for the standard questionnaire, identified and recruited potential expert participants, and analysed final research results. We played an active role in the formulation of conclusions and recommendations for the future governance of DTP genomic research. We also coordinated the preparation of a special issue of the Journal of Law, Medicine, and Ethics detailing our findings and presenting the team's recommendations. The special issue was published in 2020. We have further disseminated our findings in several international conference presentations.

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

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 overemphasis of incidental health risks. 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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QUEBEC 1000 FAMILIES (Q1K) PROJECT (TRANSFORMING AUTISM CARE CONSORTIUM)

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 Québec, by improving access and availability of resources and integrating knowledge into practice. The Québec 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 of ASD family trios (proband participant, and first-degree relatives) in families where a child has been diagnosed with an autism spectrum disorder. The CGP has developed 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 and is providing ongoing support with the management of emerging ethical questions pertaining to the implementation of the Q1K project and the TACC network.

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

Genome Canada
Genome British Columbia
Genome Québec

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.

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

Genome Canada
Genome Québec

This project aims to provide evidence that can significantly expand the benefits of the current age-based population breast cancer screening programs by supporting the transition to a risk-based approach. A population-based cohort is being assembled to evaluate the acceptability and feasibility of using a new comprehensive risk prediction web tool and a genomic profiling test. The CGP will provide health authorities with acceptable policies that address emergent socio-ethical and legal issues of implementing a personalized risk-based screening approach in Canada. To achieve this, the CGP examines five issues via a legal and sociological transdisciplinary analysis: 1) extension of the roles of health professionals; 2) integration of phone and videoconferencing technologies to provide timely clinical and informational support; 3) management of privacy when using risk calculation algorithms such as 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 also supports the research team regarding the ethics approvals required and specific ethical issues associated with the establishment of the research cohort.

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PERSONALIZED THERAPY FOR INDIVIDUALS WITH CYSTIC FIBROSIS

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. 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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APRIL 2018 MARCH 2022

MCGILL UNIVERSITY AND GÉNOME QUÉBEC INNOVATION CENTRE

Genome Canada
Genome Québec

The McGill University and Génome 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 Génome 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 Centre also hosts the Canadian Centre 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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PRECISION ONCOLOGY FOR YOUNG PEOPLE (PROFYLE 2)

Terry Fox Research Institute

The PRecision Oncology For Young peopLE (PROFYLE) program aims to transform cancer treatment in children, adolescents, and young adults by using next-generation molecular tools and cancer model systems to identify disease and patient-specific biomarkers. The project emphasizes real-time molecular profiling to personalize cancer treatment and improve outcomes. The CGP studies questions surrounding access to genetic data by parents and the use of mobile health applications when streamlining recruitment processes. Our team proposes policy recommendations for improving access to molecular profiling and associated treatment applications. The team will further identify ethical and legal issues raised by the development of mobile health technologies that facilitate patient recruitment and that promote equitable access to molecular profiling. This research will lead to the development of a points to consider document to guide PROFYLE's work toward developing a mobile application.

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

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, patientcontributed 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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INTERROGATING AND IMPLEMENTING OMICS FOR PRECISION MEDICINE IN ACUTE MYELOID LEUKEMIA

Genome Canada
Genome Québec

Acute myeloid leukemia (AML) is a leading cause of cancer-related death in young adults and a highly lethal disease in older adults. 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 web portal that will make the project's findings widely available to researchers, clinicians, and patients. The CGP undertook an extensive review of policy instruments adopted for similar functions as well as significant engagement with patients, caregivers, and healthcare providers. Notably, in-depth interviews were conducted with healthcare providers to assess their expectations for using a web portal for accessing and sharing information about AML research, which, in turn, informed the development of the portal. These efforts will also 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. The center will also organize several focus groups with patients to better understand their expectations in terms of online services to access health information and help the leucegene webportal to be more user-friendly.

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JULY 2018
JUNE 2025

MSSNG DATABASE – DATA ACCESS COMPLIANCE OFFICE

Autism Speaks Inc.

MSSNG and AGRE are the world's largest databases of genomic information collected from individuals with autism spectrum disorder (ASD) and their families. MSSNG in particular advances the goal of sequencing 10,000 families affected by ASD to answer significant remaining questions about autism, its causes, and effects. Scientists from around the world may access trillions of data points in a single database. The CGP hosts the Data Access Committee for MSSNG and AGRE, adjudicating access on the part of external researchers to these valuable resources. CGP manages the review of data access applications and grants access to qualified researchers. In 2021, the Data Access Committee approved 17 new applications.

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EPIGENOMICS SECURE DATA SHARING PLATFORM FOR INTEGRATIVE ANALYSES (EPISHARE)

Genome Canada
Genome Québec

Advances in next-generation epigenetic 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 raw data stored at multiple controlled access repositories can be a very challenging task, because access needs to be controlled to protect the 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 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 by which data will be stored, accessed and analyzed meet requirements set by international laws and standards.

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

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

H2020 euCanSHare aims to build the first one-stop-shop platform for multi-cohort cardiac data integration and exploitation, integrating computational tools and data models to a unified metadata catalogue. This consortium intends to leverage data from Canadian and European cohorts, including the Canadian Alliance for Healthy Hearts and Minds (CAHHM) and the European BiomarCare project. In collaboration with Dr. Borry (KU Leuven), the CGP 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 CGP has contributed to this initiative by translating research ethics consent and data governance documentation into standard-form profiles that can be parsed using automated means. The CGP is also producing policy documentation that addresses considerations relative to data governance and blockchain technologies.

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NOVEMBER 2018
OCTOBER 2023

HUMAN CELL ATLAS

The Klarman Family Foundation
The Chan Zuckerberg Initiative
The Helmsley Charitable Trust

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. The CGP is also in the process of producing specialized guidance relating to holistic international data governance and to pediatric populations and other vulnerable groups.

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

Canadian Institutes of Health Research (CIHR)
Genome Québec

The Global Alliance for Genomics and Health (GA4GH) is an international consortium that frames policy and establishes standards for the international exchange of genomic and health related data. Data sharing between institutions, sectors and countries is essential for accelerating research, ensuring databases are ethnically diverse, and improving health care. To guide effective and responsible data sharing, the GA4GH formed a foundational Regulatory and Ethics Work Stream (REWS). "CanSHARE Connect" will support the continued Canadian leadership and coordination of the REWS by the CGP. A central responsibility of the REWS is to develop a forward-looking policy toolkit addressing ethical and legal issues consistent with the Framework for the Responsible Sharing Genomic and Health-Related Data that was developed in 2017. This toolkit addresses consent, privacy & security, accountability, and coordinated ethics review of international collaborative research. The goal is to promote harmonization of policies and protections across countries and settings, to improve certainty and foster the trust that data sharing protects the rights and interests of participants, researchers, and society. Some recent outputs have been familial consent clauses and a revision to the ethics review recognition policy. Policy subjects expected to be completed in 2021 include return of results, participant engagement, and procedural standards for data access committees. The Consent Task Force plan on publishing additional templates of sampled consent language for genomics: familial consent clauses as well as pediatric consent clauses. The REWS also supports the implementation of the toolkit by 24 real-world genomic data sharing "Driver Projects."

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APRIL 2019 MARCH 2024

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

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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APRIL 2019 MARCH 2022

CANADIAN PARTNERSHIP FOR TOMORROW'S HEALTH (CANPATH)

Canadian Partnership Against Cancer (CPAC)

The Canadian Partnership for Tomorrow's Health (CanPath) 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 seven participating cohorts (Atlantic PATH, CARTaGENE, Ontario Health Study, Healthy Future Sask, Manitoba Tomorrow Project, Alberta's Tomorrow Project, and the BC Generations Project). The project's Ethical, Legal, and Social Issues (ELSI) Committee is hosted at the CGP and is responsible for developing ELSI infrastructure for the CanPath platform. Its goals are to bring together ELSI experts and develop relevant policies, documents, and procedures that are needed either by CanPath 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's mandate is broad, ranging from developing interoperable recruitment, access policies, and procedures to dealing with ethical issues surrounding consent, privacy, data sharing, and proposing governance structures for CanPath.

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ELSI STANDING COMMITTEE CHAIR
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APRIL 2019 SEPTEMBER 2022

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

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

EUCanCan aims to federate existing European and Canadian infrastructures to analyze and manage genomic oncology data. The CGP is co-leading the development of guidance and ethico-legal tools regarding international sharing of clinical and research oncology data. The aims include: 1) to perform a legal, policy, and normative interoperability analysis to develop guidance aimed at Canadian oncology projects when sharing personal health data with European countries and within Canada; 2) to 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) to deliver a Report these first two topics; 4) develop 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. Thus far, the CGP has compiled guidance and research related to the pan-Canadian and Canada-EU sharing of data. In collaboration with partners in Heidelberg and Bilbao, the CGP has co-authored a report to the European Commission on the intersection of federated data analysis methodologies and data protection law. The CGP intends to produce further research and guidance relating to the use of centralised platforms to store health data across Canada and the European Union.

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APRIL 2019 MARCH 2023

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

Oncopole

The goal of this project is to create a dynamic, leading North American centre for oncology research and innovation. Formed by the Goodman Cancer Research Centre, the Jewish General Hospital, the Centre hospitalier de l'Université de Montréal (CHUM), the Maisonneuve-Rosemont Hospital, the Institute for Research in Immunology and Cancer (IRIC) and the Research Institute of the McGill University Health Centre (RI-MUHC), the consortium's mission to double enrollment in oncology clinical trials and to create a dynamic biobank of samples collected during clinical trials of new drugs will have a major impact on the advancement of science for the benefit of patients. The team at the CGP will assist in the development of project governance tools and will advise the consortium on its legal and ethical obligations. In doing so, the Centre will draw on its extensive expertise in the biobanking field. The team will likewise draw on its background in the adoption of mobile health technologies for facilitating largescale genomic oncology research.

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APRIL 2019 MARCH 2023

THE CANCER GENOME COLLABORATORY

Canadian Foundation for Innovation (CFI)

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 genomic analysis, and implement services that apply new cutting-edge algorithms for the interpretation of cancer genomes. The CGP is drafting a toolkit for the national and international sharing of cancer genomic data. The CGP has also performed research concerning data identifiability standards, data protection law, and international data transfers with a particular emphasis on data transfers between Canada and the European Union.

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OCTOBER 2019 AUGUST 2022

THE MCGILL CLINICAL GENOMICS (McG) PROGRAM

Jewish General Hospital Foundation

The McGill Clinical Genomics program (McG) aims to implement hospital-based genomic medicine building on robust research to improve clinical care. McG seeks to improve disease diagnosis and risk-stratification, the efficiency of test ordering and prediction of drug responses that will deliver benefits to person-centered patient care and value to the wider healthcare system and across the CIUSSS du Centre-Ouest-de-l'Île-de-Montréal/ Center West Montreal. As part of this project, members of the Centre of Genomics and Policy will lead the Ethics and Governance Pillar and develop a set of ethics policies and templates to ensure that the Project will be able to recruit participants as well as use and share their data and samples for research purposes in an ethical and efficient manner, which complies with international best practice. Special focus will be put on COVID-19 related recruitment in light of the pandemic.

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JANUARY 2020
JANUARY 2023

ETHICAL AND LEGAL FRAMEWORK FOR DIRECT-TO-PARTICIPANT (DTP) RECRUITMENT

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

This study examines the ethical and legal issues regarding the use of internet-based Direct-to Participant (DTP) recruitment and provides guidance for its practice in stem cell research. The main objective of this project is to fill the ethical and policy gap by: 1) examining the ethical/legal issues of international DTP recruitment (for adult and minor participants) and 2) yielding concrete, practical ethical guidance and tools for Canadian researchers and REBs. In collaboration with the Program for Individualized Cystic Fibrosis Therapy (CFIT) at SickKids, the CGP will first build a case study to examine the feasibility and utility of international DTP recruitment, while producing practical, context specific governance framework and recruitment tools. Knowledge and pragmatic experience gained from the CFIT case study, along with consultations with national stakeholders (REB representatives, researchers, and policy makers), will contribute to the development of Canadian Best Practice Guidelines for DTP recruitment. As innovative and fundamental resources for Canadian REBs and researchers, the guidelines and practical tools will directly address an immediate need for clear policy and guidance for international DTP recruitment in stem cell research. They will also set the standards for Canada and internationally, consolidating Canada's position as a leader in policy development.

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JANUARY 2020
JANUARY 2023

SELF-ASSEMBLY SKIN SUBSTITUTES (SASS) FOR THE TREATMENT OF ACUTE WOUNDS OF CANADIAN BURN PATIENTS

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

Treatment for burn wounds is based on skin autografts, but when the surface that needs to be covered is more than 50 percent of one's total body surface area, autografts becomes strategic. With tissue engineering methods developed in Dr. Moulin's lab (Université Laval), autologous Self-Assembly Skin Substitutes (SASS) can be produced from only a small skin biopsy and could permanently cover all the patient wounds. This early phase clinical trial has now been accepted by Health Canada and few patients have been treated in Québec. This project will allow expanding the trial to burn units in other Canadian provinces. The aim of this trial is to evaluate this novel therapeutic approach, treating 17 patients to help skin regeneration. Dr. Moulin plans to recruit at least seven patients during the next two years and evaluate graft take and post-grafting scarring over a two-to-three-year period. Her aim is to treat most Canadian patients that have been burns over more than 50 percent of their body. SASS treatment should have economic and social benefits, as our preliminary results have demonstrated that treatment decreases morbidity caused by standard treatments and increases quality of life for patients. At the end of the clinical trial and acceptance by Health Canada, Dr. Moulin's lab will be the first in Canada to routinely treat patients with autologous reconstructed skin.

Our interdisciplinary team is composed of four internationally known researchers in regenerative medicine from two universities and of plastic surgeons working in major Canadian burn unit sites. The CGP (CGP) will assist in preparing the necessary requirements for research ethics approval (including preparing standardized recruitment procedures and protocols, consent forms and information pamphlets). This will require coordination of REB approval. The CGP will also be involved preparing documentation for the pre-CTA meetings and for regulatory approval with Health Canada.

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JANUARY 2020
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CULTURED EPITHELIAL CORNEAL AUTOGRAFTS FOR THE TREATMENT OF CANADIANS WITH LIMBAL STEM CELL DEFICIENCY

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

The aim of this project is to demonstrate through a clinical trial that autologous epithelium tissue, engineered from corneal limbal stem cells, offers an efficient strategy to treat Canadian patients with visual deficits due to limbal stem cell deficiency. As one of the leading organ reconstruction laboratories in the world, LOEX, CHU de Québec-Université Laval, will be the first to launch a multicentre trial using a human fibroblast feeder layer (instead of a murine feeder layer) to expand and preserve human stem cells in vitro, thus possibly improving vision for many Canadians. The CGP provides consultation on the socio-ethical and legal issues and assists in developing the necessary documentation for approvals from Health Canada and research ethics boards.

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JANUARY 2020
JULY 2023

THE QGPRS STUDY: QATAR GENOME POLYGENIC RISK SCORE, A PRECISION MEDICINE APPROACH TO PREVENT DIABETIC COMPLICATIONS IN THE AFFECTED QATARI INDIVIDUALS

Qatar National Research Fund
Sidra Medicine

This project aims at creating a knowledge-based platform and electronic medical record (EMR) that will integrate clinical and genomic information into clinically actionable reports for clinicians. Such platform will be flexible and adaptable to different biomarkers independently of their "omics" origin. The CGP will work to develop privacy and confidentiality policies to facilitate this integration of genomic and clinical data. Ultimately, this work will culminate in best-practice documents that will be shared with the Qatar team for local and territorial use.

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MARCH 2020
SEPTEMBER 2022

AUTISM SHARING INITIATIVE

DNA Stack

The cost of biomedical data generation has decreased exponentially, due to technologies like genome sequencing and biometric tracking devices, with a corresponding increase in the volume and diversity of data. By 2025, there will be more genomic data generated than content uploaded to YouTube. Due to the size, complexity and sensitivity of biomedical data, traditional practices for searching and analyzing large co-located datasets do not work. New technologies must be developed to connect and derive insights in a federated model from networks of heterogeneous datasets translating to clinical and pharmaceutical applications in precision health.

Autism spectrum disorders (ASD) are a set of complex conditions characterized by difficulties in social interactions and communication, as well as repetitive behaviours, which collectively affect ~1% of the population. Today, there are no approved drugs designed to treat the core features of ASD. Those affected are treated with medicines designed for other conditions. There is great promise in resolving the complex causes of ASD (and many other disorders) by sharing large volumes of biomedical data from diverse geographic populations.

In 2019, DNAstack, Autism Speaks, and AIMS-2-Trials co-founded the Autism Sharing Initiative (ASI), with the goal of uniting the world's most ambitious efforts in autism to create the first federated, global sharing network to accelerate discoveries and development of precision therapeutics.

This project will accelerate the mission of ASI by (1) building general-purpose technology to connect biomedical data into knowledge-sharing networks, (2) expanding the network to include new high-value data resources, (3) developing a platform to engage individuals with autism and their families, (4) building applications advancing precision diagnostics and therapies in autism, and (5) creating policies for responsible data sharing in the network.

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APRIL 2020
MARCH 2022

OPPORTUNITIES AND CHALLENGES OF USING EPIGENETIC TECHNOLOGIES IN DEFENCE AND SECURITY CONTEXTS

Department of National Defense (Canada)
Mobilizing Insights in Defence and Security (MINDS) program

Epigenetics refers to heritable or non-heritable changes to the DNA structure and gene activity in response to exposure to various environmental or social factors. This project aims to identify opportunities and challenges in using epigenetic technologies in the context of defence and security, with a focus on four applications: 1) exposure to nuclear, chemical or biological weapons; 2) epigenetic age (e.g., proving child soldiers' age through DNA methylation analysis); 3) mental health monitoring (e.g., PTSD); and 4) enhancement of bodily functions (memory, cognition, muscle strength) through epigenome editing. The CGP has carried out trailblazing research on the opportunities and technical, ethical and legal challenges associated with epigenetics. The CGP will organize a workshop with interdisciplinary experts on epigenetics from different regions worldwide (law, bioethics, sociology, philosophy and science) in this project. The workshop's outcomes will translate into a policy brief and briefings for interested DND/CAF officials, highlighting opportunities and challenges to effectively implementing epigenetic technologies in defence and security contexts.

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APRIL 2020
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VALIDATING, SPECIFYING & PRIORITIZING THE ETHICAL, LEGAL AND SOCIAL IMPLICATIONS OF IMPLEMENTING ARTIFICIAL INTELLIGENCE WITHIN ANTIDOPING STRATEGIES: AN INTERNATIONAL DELPHI STUDY

Fonds de recherche du Québec (FRQ)
Ministère de l'Économie et de l'Innovation (MEI)
World Anti-Doping Agency (WADA)

This study aims to explore the potential ethical, legal and social implications (ELSI) associated with the use of artificial intelligence (AI) within WADA's anti-doping strategies. This will be accomplished using a three-round, consensus-building online survey method (Delphi study) whereby the perspectives of experts and stakeholders with varied expertise and experiences will converge to inform a forward-looking approach for the ethical application, regulation and design of AI within a sport anti-doping context. These include (but are not limited to): anti-doping organization administrators; anti-doping laboratory administrators; bioinformatics experts with knowledge about AI; ELSI scholars (e.g., ethicists, social scientists, legal scholars) working on AI and/or anti-doping; and advocates of elite athletes' rights and interests. Ultimately, this will assist in better informing and facilitating 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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APRIL 2020
MARCH 2023

DOVEEGENE

Genome Canada
Genome Québec

This project aims to develop and implement a plan that raises awareness in Healthcare professionals, key opinion leaders, the Canadian public and Funding Agencies about the DOvEEgene screening test that will be made available to the public, initially in the context of a trial and following successful validation as a clinical test. Our milestone is an effective DOvEEgene Awareness Campaign developed on evidence-based strategies. Methods/Tools will be developed after analysing the literature on barriers and promoters that are relevant to implementation of a screening test and taking into account contextual factors, such as the healthcare system itself, providers, and patient groups, as well as economic impact. We will use a variety of television, newspaper, magazines, radio, features & interviews, our website, and social media. We will send an information letter to gynecologists and general practitioners to inform them about the trial using lists obtained from the College Des Médecins. This will be repeated every six months. We will invest in Continuing Medical Education of Healthcare Professionals (general physicians, gynecologists, nurses) and in lectures and events aimed at middle-age and mature women, who will be the target population.

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APRIL 2020
APRIL 2023

UN NANO-VACCIN CONTRE LES MALADIES CARDIOVASCULAIRES (AUDACE)

Fonds de recherche du Québec (FRQ)

This project aims to create a platform to revolutionize the treatment of heart disease. The project will establish a scientific basis for a nano-vaccine intended to reduce the need for medication that prevents cardiovascular events. It will simultaneously assess the ethical and legal complications raised by the development of such technology. The team at the CGP is engaged in studying the ethical and legal implications of shifting from personalized therapy (medication) to universal therapy (vaccine). Among other things, the team will determine whether the predicted transition will affect the legal responsibilities of health professionals. We focus in particular on the obligations of health professionals engaged in the care of minors and asymptomatic populations.

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MAY 2020
APRIL 2022

OF BIOBANKING AND POLICY: EMERGING ETHICAL AND LEGAL CHALLENGES DURING THE COVID-19 PANDEMIC

Social Sciences and Humanities Research Council of Canada (SSHRC)
MI4 Emergency COVID-19 Research Funding (ECRF)

The COVID-19 pandemic has demonstrated the on-going need for scientific cooperation and response at a global level. Recent research has already brought several vaccines to market, as well as possible therapeutics to combat the disease. COVID-19 specific biobanks and data repositories have been positioned at the forefront of these biomedical developments, providing researchers tools to study the novel virus at unprecedented speeds. Still, important ethical, legal, and social tensions arise between the need for rapid collection and the clinical realities faced on the ground by professionals responsible for both patient care and recruitment into research. The goal of this project is to provide policy evidence – as well as ethical and legal guidance – to inform newly created COVID-19 research infrastructures. The CGP plans to conduct a comparative analysis of existing COVID-19 international biobanking policies and launch a national survey on the lived experiences of health professionals involved in participant recruitment during the pandemic. In co-ordination with the Biobanque Québecoise de la COVID-19 and researchers in the UK, Italy, Australia, South Africa, and Hong-Kong, the CGP will ensure this work can provide objective evidence for policy development.

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MAY 2020
MARCH 2022

ELSI COMPONENT: VIRUSSEQ—CANCOGEN

Genome Canada

The Canadian COVID-19 Genomics Network (CanCOGeN) was launched to coordinate and upscale the existing genomics-based research efforts to study the SARS-CoV-2 virus and COVID-19. The CanCOGeN project is organized into components focusing on human-disease component (HostSeq) and virus (VirusSeq) to address topics unique to each. CanCOGeN-VirusSeq has multiple goals such as tracking viral transmission and exploring a multitude of pressing topics, such as the variability across patient outcomes, with each better informing both research and Public Health. Currently, Prof. Yann Joly serves as the chair of both the CanCOGeN-VirusSeq Ethics and Governance Committee and the CanCOGeN Data-Sharing Committee, while also acting as an active member the VirusSeq Implementation Committee. Lingqiao Song and Hanshi Liu are also members of the CGP (CGP) who actively contribute to the various ethical and legal topics in the project. Overall, as a part of CanCOGeN-VirusSeq, the CGP team addresses essential ethical and legal issues derived from the CanCOGeN project.

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JUNE 2020
MAY 2022

ETHICS AND POLICY PILLAR-HostSeq (CanCOGeN)

Genome Canada

In response to the ongoing COVID-19 pandemic, CGen has received federal funding to sequence the genomes of thousands of Canadians, in order to better understand the variable clinical response to COVID-19, and share resulting genomic and sequencing data through the HostSeq databank. In doing so, HostSeq will leverage existing biobanking and sample collection efforts, as well as invite interested researchers to launch their own site-specific recruitment protocols to contribute to this Canadian COVID-19 resource. The CGP developed a governance framework for the HostSeq databank, which identifies ethical, operational and oversight mechanisms governing the databank. Additionally, the CGP has prepared a list of core consent elements to assist investigators in sites across Canada in collaborating in this effort and submitting their local projects to their research ethics committees or for determining the adequacy of already-existing projects to contribute to this effort. The CGP team will also perform a pre-assessment of existing informed consent forms of contributing collections in order to assess their compatibility with the HostSeq core consent elements (or identify items that may impede use, such as data storage limitations or international sharing limitations) and will provide ongoing policy consultation to the HostSeq databank.

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JULY 2020
MARCH 2023

ETHICAL LEGAL EXPERTISE – COVID-19 IMMUNITY TASK FORCE (CITF)

The Government of Canada Public Health Agency of Canada (PHAC)
Canadian Institutes for Health Research (CIHR)

The COVID-19 Immunity Task Force (CITF) is collecting blood samples and survey data for the purposes of assembling a national repository of data relating to seroprevalence and immunization, as well as vaccine surveillance. The CITF is coordinating numerous local and multi-center seroprevalence studies, and is collaborating with Canadian Blood Services, Héma-Québec, and the National Microbiology Laboratory, among other partners, to collect and interpret data in a harmonised manner. The Centre of Genomics and policy is responsible for creating ethico-legal deliverables for the CITF and for guiding the data governance initiatives thereof.

To this end, the CGP has produced a data governance framework, template informed consent materials, and retrospective consent guidance for legacy datasets and samples. Further, the CGP has been actively involved in the CITF's efforts to ensure the normative interoperability of its cohorts, through direct engagement with study coordinators and CITF leadership.

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SEPTEMBER 2020
OCTOBER 2022

INNOVE-ONCO – TECHNOLOGICAL AND ORGANIZATIONAL INNOVATIONS GO HAND IN HAND: A COLLABORATIVE MODEL TO RENDER ONCOGENETICS MORE FLEXIBLE, ACCESSIBLE AND EFFICIENT

Fonds de recherche Santé Québec (FRQS)

The CHU de Québec-Université Laval has developed a "collaborative oncogenetic model" (COM) aimed at improving access to genetic counseling services and minimizing delays for genetic tests for patients. The Oncopole project seeks to understand the context in which the COM was developed and implemented, and to document the lessons that can be drawn from it to optimize the delivery of local and regional oncogenetics services in Quebec. CGP missions: - Review of the literature on legal, regulatory and ethical issues related to the extension of the role of non-genetic health professionals and the establishment of a register of patients benefiting from genetic counseling and testing for cancer hereditary breast and ovary. - Comparative law analysis to identify the main legal variations and promote better coordination of the legal texts of the different national systems.

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SEPTEMBER 2020
JANUARY 2023

TOWARDS AN EPIDERMOLYSIS BULLOSA CLINICAL TRIAL WITH TISSUE-ENGINEERED SKIN AFTER EX VIVO GENE THERAPY CORRECTION

Canadian Institutes of Health Research (CIHR)
Natural Sciences and Engineering Research Council of Canada (NSERC)
The Social Sciences and Humanities Research Council (SSHRC)
Université Laval Networks of Centres of Excellence (NCE)
Stem Cell Network (SCN)

The aim of this project is to demonstrate through a clinical trial that autologous tissue-engineered skin substitute, produced with fibroblasts and epithelial stem cells previously corrected ex vivo by gene therapy, offers an efficient strategy to treat Canadian patients suffering from dystrophic epidermolysis bullosa (DEB). As one of the leading organ reconstruction laboratories in the world, LOEX, CHU de Québec-Université Laval will be the first to launch a clinical trial using a bilayered human skin substitute (instead of a single cell type) in which the adhesion of epidermis to the dermis is functional in vitro before grafting on patients, thus possibly providing a curative treatment for the recurring wounds of many Canadians. The CGP (CGP) will assists in preparing the necessary requirements for research ethics approval (including preparing standardized recruitment procedures and protocols, consent forms and information pamphlets). The CGP will also be involved preparing documentation for the pre-CTA meetings and for the regulatory approval with Health Canada.

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NOVEMBER 2020
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SECUREDATA4HEALTH

Canadian Foundation for Innovation (CFI)

Data has the potential to dramatically transform biomedical research and health care. In particular, we are now in an era where genomes can be systematically sequenced and provide fundamental insights into our predisposition to diseases, our response to therapies and how our health can be affected by our environment. Recognizing this, Canada has been at the forefront of the genomic revolution, making a combined investment of more than $2.4 billion in this field. However, as a global scientific community, our ability to interpret and utilize this type of information is still only at a nascent stage. Specifically, to fully realize the benefits of genomic and health data, we need infrastructure to securely store, analyse and employ this information without compromise. Moreover, when appropriately consented, we need tools to share these data both nationally and internationally, since a critical mass of samples is needed for advanced machine learning approaches and to enable key biomedical discoveries. Our SecureData4Health proposal will create within Canada the computational and software infrastructure needed to safely store, interpret and share the genomic and health information that is rapidly expanding within our centres and hospitals. It will also facilitate access to the wealth of complementary information being made available across the world. The SecureData4Health infrastructure will be deployed within the existing host sites of Compute Canada, allowing our team of scientists and users easy access to the technologies needed to reap the full benefits of their data, without the need to duplicate resources. Finally, our project will provide innovative data sharing modalities where the security and confidentiality of participants' data will be paramount. It will enable Canada to play a leading role in the challenging but critically important movement towards international health data sharing.

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NOVEMBER 2020
DECEMBER 2022

DEVELOPPEMENT D'UN CADRE ETHIQUE ET LEGAL POUR LE DEPLOIEMENT DES ACTIVITES DU RQDM ET L'HARMONISATION DU CONSENTEMENT DES PATIENTS / DEVELOPMENT OF AN ETHICAL AND LEGAL FRAMEWORK FOR THE DEPLOYMENT OF RQDM ACTIVITIES AND THE HARMONIZATION OF PATIENT CONSENT

Ministère de la Santé et des Services sociaux (MSSS)
Revue Québécoise de didactique des mathématiques (RQDM)

The Réseau québecois de diagnostic moléculaire (RQDM) is an initiative that aims to meet the current and future needs of the health and social services network in the field of molecular diagnosis and personalized medicine, particularly in the areas of rare disease diagnosis and cancer. It also aims to repatriate analyses performed in private national and international laboratories into the Québec public health and social services network. The CGP works on the development of an ethical and legal framework for the implementation of RQDM's activities and to harmonize consent for patients that are prescribed a molecular analysis in genetics or oncology. Accordingly, the CGP is developing template consent forms that address the following elements: compliance with ethical standards, management of incidental findings, storage and sharing of sequencing data and clinical information, storage of samples for future clinical use, and access to samples and data resulting from clinical analyses for research purposes.

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JANUARY 2021
DECEMBER 2023

SMARTPHONE CROWDSOURCED MEDICAL DATA FOR BIOMEDICAL RESEARCH: ADDRESSING THE ETHICAL, LEGAL AND HEALTH POLICY CONCERNS

Fonds de Recherche du Québec (FRQ)

Smartphone applications for health are being increasingly used as a platform to collect and share large volumes of crowdsourced personal health data for biomedical research and algorithm training. Consumer genetics products are similarly allowing individuals to have direct access to their own genetic data and to share such data with researchers. Using smartphone and genetic data in these ways presents numerous opportunities to expand biomedical knowledge, though it also raises certain risks. Some of these include risks to personal privacy and risks associated with unclear ethical and legal obligations on the part of app developers and researchers. In this project, the CGP collaborates with Belgian partners to mitigate these risks. We do so by determining how smartphone applications and other mobile tools that collect health data work in practice and by addressing legal, ethical, and regulatory uncertainty in both Canada and the European Union. We will use this evidence to develop health policy guidelines that will enable smartphone data to be used safely, in a manner that protects users and the public. In doing so, we will assure that such data will contribute to improved health outcomes by expanding biomedical knowledge and making health more effective and efficient.

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JANUARY 2021
JUNE 2024

THE QUEBEC SMARTCARE CONSORTIUM

Ministère de l'Économie et de l'Innovation (QC)

The Quebec SmartCare (Soins intelligents) Consortium is an innovative research project centred on the Opal patient portal (opalmedapps.com) at the Research Institute of the McGill University Health Centre (RI-MUHC) that is designed to address the challenges caused by the siloing of data in the Quebec healthcare system. It comprises a unique group of public and private partners with expertise and interest in patient-centered care, mHealth technology, and AI research. Working together, the consortium partners will strengthen the patient-centered technology of the existing Opal patient portal, enable secure data flow from wearable devices into Quebec hospitals, and collect real-world data for artificial intelligence and real-world evidence research.

The Centre for Genomics and Policy will: (1) examine specific ethico-legal issues associated with access to data, (2) develop a governance framework for access, (3) develop with stakeholders a "Collaboration with Industry" policy, a Code for Collaboration with Industry, and a go/no-go checklist for agreements with industry, and (4) implement an Access system and coordinate review/adjudication of access requests by researchers.

The work will put in place solid frameworks for data governance and commercialization/technology transfer that are expected to persist well beyond the lifetime of the QSCC and will help foster continued collaboration amongst the partners.

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APRIL 2021
MARCH 2022

REGENERATIVE MEDICINE CHARTER UPDATE PROJECT

Stem Cell Network (SCN)

Advances in regenerative medicine challenge both traditional legal classifications and professional ethics norms. The development of a Regenerative Medicine Charter by the CGP, founded on both international human rights and recent policy guidance, seeks to frame the future conduct of research in regenerative medicine. To do so, we examine the current international ethical and legal landscape concerning cellular genomics, bioengineering, human genome editing, and stem cell research in order to propose key pillars for the Regenerative Medicine Charter. In particular, we posit that the respect of the human right to science, to health, and to non-discrimination as well as the principles of quality/safety, integrity/accessibility, and transparency/accountability could guide the ethical future of regenerative medicine. Hopefully, the Charter will bring together and inspire the diverse communities of policymakers, scientists, clinicians, as well as patients and their families as they face the challenges of regenerative medicine.

PRINCIPAL INVESTIGATOR
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JULY 2021 JULY 2022

GA4GH GENOMIC DATA SHARING TOOLS AGAINST COVID-19 FUNDING OPPORTUNITY

Canadian Institutes of Health Research (CIHR)

The COVID-19 outbreak has highlighted the need for genomic data standards to share high-quality genomic and health data rapidly. Researchers have started to share viral and host sequence data at an unprecedented pace, a first step in creating vaccines in record time. Sharing this data is necessary to understand human diseases and eventually help patients. Doing so requires the community to agree on standard methods for collecting, storing, transferring, accessing, and analyzing data.

The Global Alliance for Genomics and Health (GA4GH) GA4GH brings together 1,000+ individual contributors and 660+ organizational members across 35+ countries to accelerate progress in genomic research and human health by cultivating a common framework of standards and harmonized approaches for effective and responsible data sharing.

GA4GH will develop, refine, and adapt GA4GH standards and open-source tools to facilitate research data sharing for COVID applications and the greater infection disease community. This project will support the GA4GH to bring in additional personnel, support the existing team, and drive engagement with the Canadian COVID research community. Collectively, these efforts will ensure the rapid and timely research response to the current phase of the COVID-19 pandemic in Canada and around the globe, which emerging variants of concern will heavily impact.

PRINCIPAL INVESTIGATOR
GOODHAND Peter

COLLABORATOR
JOLY Yann

JULY 2021 JULY 2025

A CGMP FACILITY FOR PERSONALIZED TISSUE ENGINEERING

Canadian Foundation for Innovation (CFI)

Rapid advances in stem cell research and tissue engineering have put regenerative medicine at the forefront of innovation in the area of patient-oriented therapeutic applications. Combining stem cells cultured from patient biopsies with tissue engineering has the potential to revolutionize grafting practices by offering viable and feasible solutions not only to healing complex wounds but also to the shortage of donated organs. However, the clinical translation, from bench to bedside, of these personalized tissue engineering products is slow and often hampered by both a lack of resources and access to appropriate facilities that meet the safety and quality standards required for clinical research. Therefore, the aim of this project is to provide Canada with the certified Good Manufacturing Practice (cGMP) facility required to conduct the clinical research essential in concretizing the applications of personalized tissue engineering for regenerative medicine.

PRINCIPAL INVESTIGATOR
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CO-INVESTIGATOR
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ACADEMIC ASSOCIATE
NGUYEN Minh Thu

AUGUST 2021 MARCH 2022

COMPARATIVE REVIEW OF HEALTH DATA SHARING IN CANADA - PHAC

Public Health Agency of Canada (PHAC)

The CGP has developed an expert report delivered to the Public Health Agency of Canada (PHAC), detailing how Canadian data protection law, Canadian public health legislation, and biomedical research ethics guidance affect the potential to share health-related information for public health purposes, amongst distinct Canadian health-sector institutions.

This report helps the Public Health Agency of Canada, and the Expert Advisory Group on the development of a Pan-Canadian Health Data Strategy, to propose recommendations to facilitate the sharing and stewardship of biomedical information to enable improved healthcare delivery and inform public health efforts.

PRINCIPAL INVESTIGATOR
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+ 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.

HGEN 674

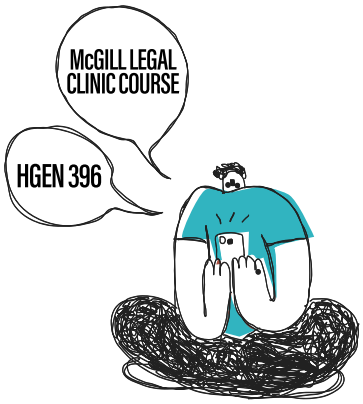
RESEARCH INTERNSHIP IN GENOMICS AND POLICY

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

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.

INTERN STUDENTS

The CGP offers internship opportunities for law students via the McGill Legal Clinic Course and undergrad students at the Department of Human Genetics via HGEN 396. Through these internships, students have the opportunity to be involved in various research activities and projects relating to the multidisciplinary work at the Centre.



"I absolutely enjoyed my research internship at the Centre of Genomics and Policy. Many employees are fellow students or recent graduates making for a very friendly work environment. Opportunities to exchange ideas and learn abound, as the projects and research conducted by the CGP are varied, multidisciplinary, and current."

NATALIE KELLER

McGILL LEGAL CLINIC COURSE

DENA KIA

McGILL LEGAL CLINIC COURSE

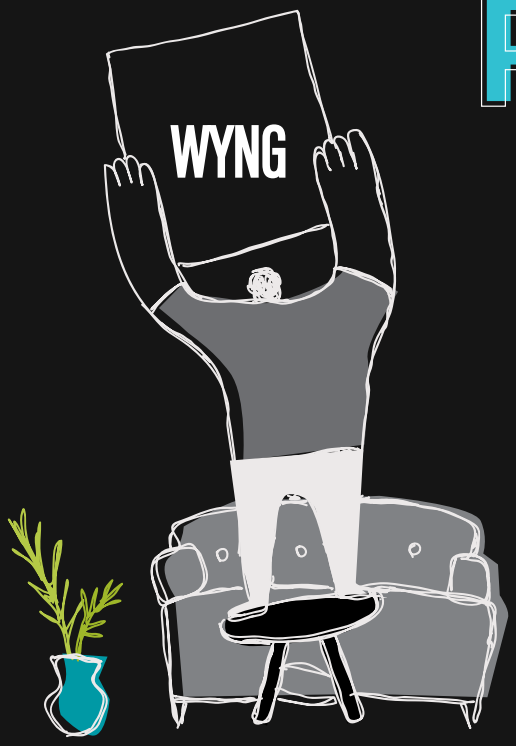
"I've really enjoyed my time working as an intern at the CGP. The best part of the internship for me has been the amazing colleagues I have had the privilege to meet, work with and learn from. As a law student, I've also really enjoyed becoming familiar with genetic discrimination laws in different countries and doing research at the intersection of law, medicine and ethics."

"I had the opportunity to work as an intern in creating a harmonized survey on genetic discrimination under the supervision of Dr. Yann Joly and Dr. Gratien Dalpe. My experience with the CGP gave me a helpful and professional environment in which to further my learning regarding the intersections of medicine, law, ethics, and policy. By being part of the CGP and by collaborating with the exceptional people in the office, I broadened my understanding and developed a richer perspective of the complex landscapes of genetics, health, and policy."

RIM METINA-BELKNAP

HGEN 396

VISITING SCHOLAR PROGRAM



WYNG FOUNDATION

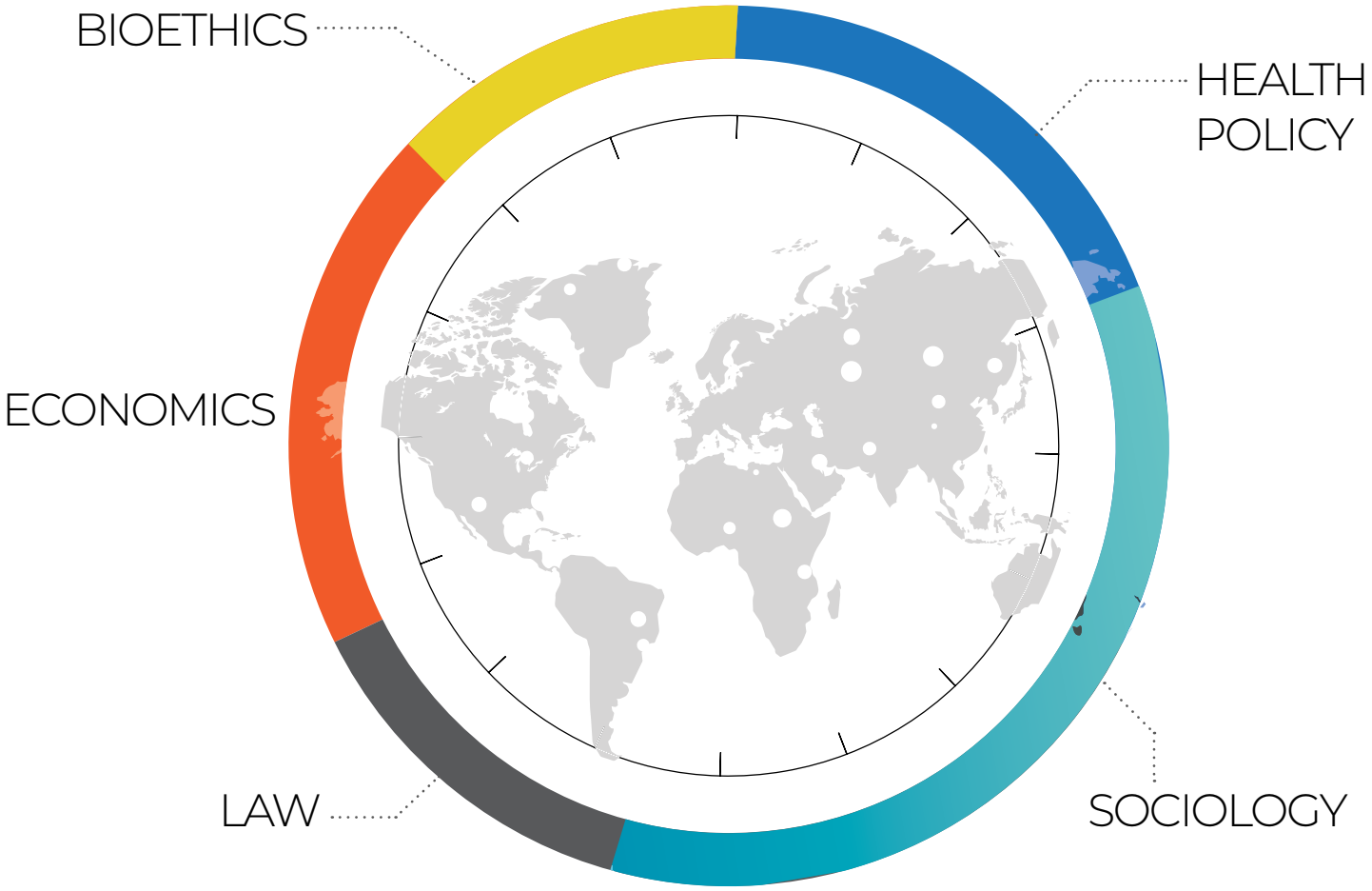
Thanks to a collaborative agreement with the Centre for Medical Ethics and Law of the University of Hong Kong (CMEL) and the WYNG Foundation, we are pleased to support the CGP / Wyng Trust Visiting Scholars Program.

In March 2021, the Centre for Medical Ethics and Law of the University of Hong Kong (CMEL) and the WYNG Foundation, in collaboration with the Centre of Genomics and Policy (CGP), were in the process of planning a conference on "Health and Artificial Intelligence: Law, Ethics and Society", where Professors Bartha Knoppers, Yann Joly ("Data sharing in the context of learning healthcare systems") and Ma'n Zawati ("Smartphone apps for genetic research and AI algorithms training") were set to present, along with fellow colleagues from the CGP. Due to the ongoing COVID-19 pandemic, the conference was postponed. There remains hope that, as pandemic restrictions slowly ease around the globe, travel to Hong Kong will resume.

GENETIC DISCRIMINATION OBSERVATORY

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

The Genetic Discrimination Observatory (GDO) is a network of international experts and collaborators from over 23 jurisdictions dedicated to researching and preventing genetic discrimination.



Document the issue of genetic discrimination in a scientific and evidence-based manner.

GDO OBJECTIVES

Use this information to assess existing normative models work best and develop new ones.

Engage the public, policymakers and other stakeholders in a collective debate about genetic discrimination.

GDO INTEREST

THE GDO CONTINUES TO GROW TO BECOME THE HUB FOR INFORMATION ON GENETIC DISCRIMINATION. IN 2021, THE WEBSITE WAS VISITED 36,245 TIMES.

JUNE 2021

ANNUAL RETREAT

The GDO held its second annual retreat online on June 7 and 9, 2021.

COLLABORATIVE RESEARCH

GDO RESOURCES

In collaboration with the GA4GH-REWS, the GDO has generated its first tool: "Genetic Discrimination: Implications for Data Sharing Projects (GeDI)".

GDO FUNDING APPLICATION:

SSHRC Connection Grant application for holding an in-person GDO conference in Montreal in 2022.

WWW.GDO.GLOBAL

NEW MEMBERS

From Iceland, Ukraine and Chile joined the GDO's International Expert Panel.

DEC 2021

The Share Your Story webpage is now offered in English, French and Spanish in Mexico, Canada, the USA and UK.

The GDO initiated an international policy Delphi study to identify the essential features of an optimal genetic non-discrimination policy.


CANADA
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CANADA
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UNITED KINGDOM
Edward Dove
CANADA
Yvonne Bombard
ICELAND
Hrefna D. Gunnarsdóttir
UNITED STATES
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IRELAND
Aisling Depaor
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Palmira Granados M.
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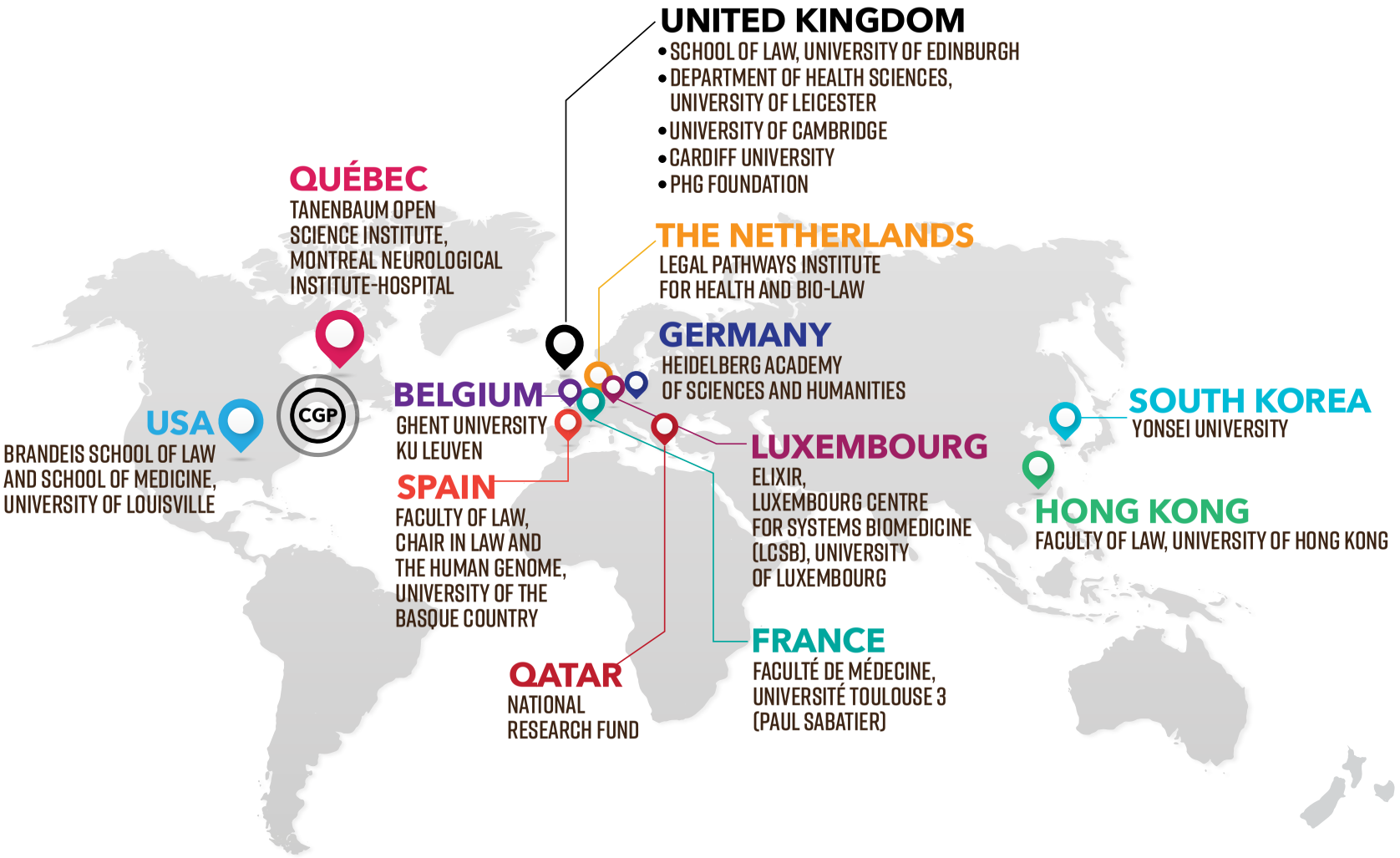
CGP INTERNATIONAL COLLABORATIONS



GA4GH — GLOBAL ALLIANCE FOR GENOMICS AND HEALTH

HCA — HUMAN CELL ATLAS

IHEC — INTERNATIONAL HUMAN EPIGENOME CONSORTIUM

HeLTI — HEALTHY LIFE TRAJECTORIES INITIATIVE

IRDiCRC — INTERNATIONAL RARE DISEASES RESEARCH CONSORTIUM

ICGC — INTERNATIONAL CANCER GENOME CONSORTIUM

ICDA — INTERNATIONAL COMMON DISEASES ALLIANCE

TEAM PUBLICATIONS 2021

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