

Vasiliki Nataly Rahimzadeh  
PhD Candidate

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Curriculum Vitae

September 2018

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Common Acronyms:

CIHR: Canadian Institutes for Health Research

MUHC: McGill University Health Center

GA4GH: Global Alliance for Genomics and Health

GC: Genome Canada

## A. IDENTIFICATION

**Name** Vasiliki Nataly Rahimzadeh

**Office Address** **Department of Family Medicine**  
5858 Chemin de la Côte-des-Neiges, Suite 300  
Montreal, Quebec, H3S 1Z1

**Department of Human Genetics**  
Centre of Genomics and Policy  
740 Ave Docteur Penfield, Suite 5200  
Montreal, QC, H3A 0G1

**Telephone** 514.887.7030

**Email** [vasiliki.rahimzadeh@mail.mcgill.ca](mailto:vasiliki.rahimzadeh@mail.mcgill.ca)

**Date of Birth** September 14, 1989

**Place of Birth** Orlando, Florida (USA)

**Citizenship** USA

**Languages** English, Greek, Spanish, Farsi (Elementary) French (Elementary)

## B. EDUCATION

### 1. Graduate

2014 – 2019  
(expected) PhD in Family Medicine, Biomedical Ethics Specialization  
Department of Epidemiology & Biostatistics, McGill University  
Thesis: *Evaluating the gap between research ethics review governance and data sharing in the pediatric data-intensive sciences*  
Supervisors: Bartha Maria Knoppers, PhD, L.L.B and Gillian Bartlett, PhD  
Funding: Vanier Canada Graduate Scholarship (CIHR #359258)

2012 - 2014 MSc in Experimental Medicine, Biomedical Ethics Specialization  
Faculty of Medicine, McGill University  
Thesis: *On the ethics of engagement: health-related quality of life in terminally ill children and adolescents*  
Supervisors: Carolyn Ells, PhD and Gillian Bartlett, PhD  
Funding: David McCutcheon Pediatric Palliative Care Fellowship

## 2. Undergraduate

2008 - 2012      Bachelor of Science  
College of Natural Resources, University of California Berkeley  
Major: Microbial Biology  
Minor: Global Poverty and Practice  
Funding: Father Tom Paris Undergraduate Scholarship

## C. APPOINTMENTS

### 1. National Appointments

2017 – present      Canadian Institutes of Health Research (CIHR) Standing Committee on Ethics

### 2. Research Appointments

2017 - 2018      **Coordinator**, Ethics Review Equivalency Task Team of the Global Alliance for Genomics and Health

2016 - 2018      **Lead**, Pediatric Data Sharing Working Group, Pediatric Task Team of the Global Alliance for Genomics and Health

2015 - 2016      **Coordinator**, Ageing and Dementia Task Team of the Global Alliance for Genomics and Health

2011-2012      **Microbiology lab lead**, Department of Civil and Environmental Engineering, University of California Berkeley, Nelson Lab

2010 - 2012      **Undergraduate researcher**, United States Department of Agriculture, Baker Lab

### 3. Other Appointments

2014 - 2018      **Elected Council Member**, Department of Family Medicine representative to the Post Graduate Student Society, McGill University

2012 - 2014      **Elected Council Member**, Department of Experimental Medicine representative to the Post Graduate Student Society, McGill University

## D. SPECIAL HONOURS, AWARDS, RECOGNITION

2013	<b>Admitted</b> to the Golden Key Graduate Honour Society McGill University
2012	<b>Student Abstract Winner</b> Pediatric Bioethics Conference, Seattle Children's Hospital
2010	<b>Sys Collins Service and Membership Award</b> Chi Omega Mu Chapter, University of California Berkeley

## E. TEACHING

### 1. McGill Courses

#### 1a. Undergraduate

##### FMED609 Transition to Clinical Practice Organizational Ethnography (3 credits)

Department of Family Medicine, McGill University

Mandatory course in the Transition to Clinical Practice program for second-year undergraduate medical students.

My Role: Small group facilitator under Professor Peter Nugus. As a small group leader, I lectured, graded and supported 2 cohorts of 20 second-year medical students over 2 years (over 48 teaching and assessment hours).

- Spring/Summer 2015: five, 3-hour sessions = 15 in-class teaching hours (21 students)
- Spring/Summer 2016: five, 3-hour sessions = 15 in-class teaching hours (19 students)

#### 1b. Graduate

##### FMED 625: Qualitative Research Methods in Health (3 credits)

Department of Family Medicine, McGill University

Mandatory course for graduate students in both PhD and MSc programs in Family Medicine

My Role: Teaching Assistant and guest lecture for class on "Ethics in qualitative research" with Professor Charo Rodriguez

- Fall 2015: eleven, 3 hour sessions—33 in-class TA hours (21 students)
- Fall 2016: eleven, 3 hour sessions –33 in-class TA hours (23 students, 7 Swiss online/blended learning students)
- Fall 2017: eleven, 3 hour sessions –33 in-class TA hours (24 students)
- Fall 2018: eleven, 3 hour sessions—33 TA hours (17 students)

##### NUR2642 Ethics in Advanced Nursing Practice (3 credits)

Ingram School of Nursing, McGill University

Mandatory course for Direct Entry and Master's Degree students in nursing

My Role: Teaching assistant responsible for all administrative course support, student grading. I was involved in developing a new course syllabus and updated course content in 2015

- Winter 2014: twelve 3-hour session = 42 in class TA hours (32 students)
- Winter 2015: twelve 3-hour session = 42 in class TA hours (34 students)
- Winter 2016: twelve 3-hour session = 42 in class TA hours (31 students)

## 1c. Graduate Program Development

### ONCO635 Qualitative and Psychosocial Methods in Health Research (3 credits)

Department of Experimental Surgery, McGill University

Mandatory course for students in the professional graduate certificate program in the Oncology and Palliative Care stream

**My Role:** Curriculum developer and instructor for the mandatory qualitative research methods course as part of the newly accredited Integrated Graduate Program in Oncology under the *Psychosocial and Palliative Care* stream. The objective of the MSc program in Oncology is to expose students to principles, practices and research domains related to oncology, while reinforcing the multidisciplinary/interdisciplinary nature of cancer research and clinical care. The program caters to clinical professional backgrounds, including but not limited to nursing, medicine, nursing, occupational therapy/physiotherapy, psychology, social sciences, statistics, and related disciplines or specialties.

### Graduate training and online module development for research ethics in primary care

#### **Content curator**

Department of Family Medicine, McGill University

## 2. University of California Berkeley

### 2a. Undergraduate

#### PMB170 Contemporary Applications in Plant Biotechnology (3 credits)

Department of Plant and Microbial Biology, University of California Berkeley

Elective course for Plant Biology and Microbial Biology students in the Department of Natural Resources.

My Role: Course Reader and Teaching Assistant under Professor Barbara Baker.

Responsible for lecture content preparation and assessment of final semester capstone projects.

- Fall 2010: twelve, 2 hour lab sessions—24 total TA instruction hours (28 students)
- Fall 2011: twelve, 2 hour lab sessions—24 total TA instruction hours (31 students)

## 3. Trainee Supervision

### 3a. Master of Science Trainees

- |    |              |  |
|----|--------------|--|
| 1. | 2015-present | Thesis Committee Member for Nina Mamishi<br>Family Medicine<br><u>Thesis:</u> Barriers and Facilitators to Breast Cancer Screening: A Quantitative Study among Iranian Immigrant Women in Montreal |
|----|--------------|--|

### 3b. Juris Doctor Candidate Mentoring

2. 2017 - present Research mentor for J. Parker Mincey  
Syracuse University College of Law, Syracuse NY (USA)  
Thesis: *Ethereum Smart contracts and specific legal norms in contract law*
3. 2017 - present Amanda Zihan Wang  
Juris doctor candidate  
Syracuse University College of Law, Syracuse NY (USA)

### 3c. Graduate Student Mentoring

1. 2017 - present Ran van der Wal, PhD Candidate (2018 Vanier recipient)  
Vanier Canada Graduate Scholarship application mentor  
Department of Family Medicine, McGill University
2. 2017 - present Amanda Zihan Wang  
Juris doctor candidate  
Syracuse University College of Law, Syracuse NY (USA)
3. 2016 Nadia Sourial, PhD Candidate (2017 Vanier recipient)  
Vanier Canada Graduate Scholarship application mentor  
Department of Family Medicine, McGill University
4. 2016 Ayat Salman, PhD Candidate  
Vanier Canada Graduate Scholarship application mentor  
Department of Family Medicine, McGill University
5. 2013 - 2015 Laura Crimi  
Department of Family Medicine (McGill University)  
Thesis: *Barriers to Personalized Medicine in Pediatrics: The Implementation of a Novel Pharmacogenomic Test for Pediatric Neuroblastoma*  
Funding: Réseau de Médecine Génétique Appliquée 2014 Gérard – Bouchard Fellowship

### 4. Invited Presentations, Lectures and Seminars

1. July 3, 2018 **Invited expert.** Genomic Security with EncrypGen Gene-chain and the DNA Token. Blockchain in Healthcare Webinar Series.



2. February 23, 2018 **Invited expert.** Blockchain and data sharing. Webinar hosted by the Syracuse College of Law. Available from: <https://www.youtube.com/watch?v=SQO0HSMqhY4&feature=youtu.be>
3. February 21, 2018 Workshop presenter. Innovations and Challenges in Recruiting Children with Neurodevelopmental Disorders in Research  
National Core for Neuroethics, University of British Columbia
4. October 23, 2017 Ethics in qualitative health research  
Department of Family Medicine, FMED625 Qualitative Research Methods in Health, Guest lecture
5. May 5, 2017 Policy relevant truth telling in ethics governance of the data-intensive sciences: a tale of two(?) narratives. Invited workshop plenary. Annual Meeting of the Canadian College of Medical Geneticists in Montreal, QC (CA).
6. May 12, 2016 Evaluating the gap between research data sharing and ethics governance in the pediatric data intensive sciences  
Department of Family Medicine, Annual Research Symposium Vanier Scholarship Award recipient address
7. October 24, 2015 Ethics in qualitative health research  
Department of Family Medicine, FMED625 Qualitative Research Methods in Health, Guest lecture

## 8. Program Development Activities

1. 2018 - present **Course/curriculum developer**  
ONCO635 Qualitative and Psychosocial Methods in Health Research  
Department of Experimental Surgery, McGill University
2. 2016 - present **Content curator and module developer**  
Research ethics in primary care and family medicine research  
Department of Family Medicine, McGill University

## F. ADMINISTRATION/SERVICE

### 1. Journals

#### 1a. International Editorial Boards

1. 2016 – present Frontiers in Genetics

#### **1b. Ad hoc Reviews**

1. 2015 – present BMC Family Medicine (1 manuscript)
2. 2015 – present Personalized Medicine (1 manuscript)
3. 2015 – present International Archives of Nursing Healthcare (1 manuscript)
4. 2017 – present Canadian Medical Association Journal (1 manuscript)
5. 2018 – present Scientometrics (1 manuscript)

#### **1c. Journal Editing**

1. May 2018 Co-editor of Special Conference Proceedings Issue, *McGill Journal of Medicine*  
Family Medicine Graduate and Research Symposium
2. 2016 Co-editor of Special Issue, *Biopreservation and Biobanking*  
International Biobanking and the BioSHaRE-EU experience  
Volume 14, Issue 3

### **2. Grants**

#### **2a. Ad hoc Reviews**

1. 2012 – 2013 MUHC-Pre-implantation Genetic Diagnosis Ethics Review Committee, McGill University Reproductive Health Centre, Royal Victoria Hospital

### **3. Conferences**

#### **3a. Abstract/Paper Reviews for International Conference**

1. 2015 – present Canadian Bioethics Society Annual Meeting (12 abstracts)

#### **3b. Conference Activities**

##### **International**

1. 2017 **Workshop and satellite meeting organizer** for the Ethics Review Equivalency Task Team of the Global Alliance for Genomics and Health: “Practical guidance for ethics review mutual recognition” at the 5<sup>th</sup> Plenary of the Global Alliance for Genomics and Health held in Orlando, FL. October 15-17, 2017
2. 2017 **Panel organizer and session moderator** at the UNESCO Chair in Bioethics 12<sup>th</sup> World Conference on Bioethics, Medical Ethics and Health Law: “Genetics and Ethics”, Limassol (Cyprus)
3. 2016 **Workshop and satellite meeting organizer** for the Ethics Review Equivalency Task Team of the Global Alliance for Genomics and Health: “Practical guidance for ethics review mutual recognition” at the 5<sup>th</sup> Plenary of the Global Alliance for Genomics and Health held in Orlando, FL.
4. 2016 **Workshop and satellite meeting organizer** for the Pediatric Task Team of the Global Alliance for Genomics and Health: “Developing points to consider for pediatric data sharing” held in Vancouver, BC.
5. 2015 **Panel organizer and session moderator** at the UNESCO Chair in Bioethics 10<sup>th</sup> World Conference on Bioethics, Medical Ethics and Health Law: “Advances in Genetics”, Jerusalem (Israel)

#### National

1. 2016 **Pre-conference workshop organizer and session moderator** for the Canadian Bioethics Society Annual Conference: “Taking a provincial, national and international pulse of research ethics review “equivalence” held in Montreal, QC.
2. 2016 **Workshop organizer** for the Pediatric Task Team of the Global Alliance for Genomics and Health: “**Key Implications of Data Sharing** in pediatric genomics: points to consider for **KIDS**” at the 4<sup>th</sup> Plenary of the Global Alliance for Genomics and Health held in Vancouver, BC.
3. 2016 **Pre-conference workshop organizing committee** for the Pediatric Ethics Affinity Group at the Canadian Bioethics Society Annual Conference, Montreal (QC).

4. 2015 **Pre-conference workshop organizing committee** for the Pediatric Ethics Affinity Group Meeting at the Canadian Bioethics Society Annual Conference, Toronto (ON).

#### **McGill University**

1. 2017 **Organizing committee member and Tannenbaum Fellow** for the Isaac Tannenbaum Annual Resident Research Day for the McGill University Department of Family Medicine planned for June 1, 2018 in Montreal, Quebec.
2. 2017 **FMGSS Organizing Committee** for the Third Annual McGill Family Medicine Research Division and Graduate Student Society Symposium held May 4, 2017 in Montreal, Quebec (~ 55 attendees).
3. 2018 **FMGSS Organizing Committee** for the Fourth Annual McGill Family Medicine Research Division and Graduate Student Society Symposium held May 30, 2018 in Montreal, Quebec (~120 attendees).

#### **4. Administrative Responsibilities**

1. 2015 – present **Administrator**, Canadian Bioethics Society

## 5. Committees

### 5a. McGill University and greater Montreal

1. 2017 - present **Chair**, Dawson College Research Ethics Board
2. 2017 - present **Member**, Montreal Neurological Institute and Hospital, Research Ethics Committee
3. 2017 - present **Member**, Family Medicine Resident Scholarly Activities Committee  
Department of Family Medicine, McGill University
4. 2014 - 2017 **Member**, Dawson College Research Ethics Review Committee
5. 2014 - 2018 **Member**, Jewish General Hospital Research Ethics Review Committee
6. 2012 - 2013 **Member**, MUHC-Pre-implantation Genetic Diagnosis Ethics Review Committee, McGill University Reproductive Health Centre, Royal Victoria Hospital
7. 2012 - 2013 **Member**, Montreal Neurological Institute and Hospital, Research Ethics Committee

### 5b. National

1. 2014 – present **Member**, Maternal Infant Child Youth Network (MICYRN)

## 6. Professional Development

1. 2018 **Attendee**, Putting Patients at the Center of Research. Petrie-Flom Center for Health Law Policy, Biotechnology and Bioethics at Harvard Law School, June 29, 2018 Cambridge (MA).
2. 2018 **Attendee**, The Development and Certification of Decision Aids: Promoting Shared Decision Making for Patients with Serious Illness. Petrie-Flom Center for Health Law Policy, Biotechnology and Bioethics at Harvard Law School, April 18, 2018 in Cambridge (MA).
3. 2018 **Participant**, Blockchain in Government Workshop. Canadian Institute on Governance in Ottawa (ON).

4. 2017 **Attendee**, McGill University Teaching and Learning Services. “Academic Dossier: Teaching and Research Statements” held at McGill University, November 13, 2017.
5. 2017 **Attendee**, Centre for Social and Cultural Data Science 2017 Computing and Math Summer (p)refresher workshop for graduate students: “R Camp” held at McGill University, Aug 23- 25<sup>th</sup> 2017.
6. 2016 **Participant**, Institute for Health and Social Policy Research to Policy Dragon’s Den: “Immigrant and Refugee Settlement Policy in Canada” held at McGill University June 6-10, 2016. [Dragon’s Den grand prize finalist].
7. 2016 **Participant**, Arizona State University Centre for Nanotechnology in Society 3<sup>rd</sup> Annual Winter School: “Anticipatory governance, responsible innovation and social studies on emerging technologies” held at the Saguaro Lake Ranch, Tempe AZ (USA) January 3 - 10, 2016.
8. 2015 **Attendee**, McGill University Teaching and Learning Services “Learn to Teach Day” full-day training on effective teaching skills, assessment in the social sciences and fostering academic success at the under/graduate level held at McGill University.
9. 2014 **Attendee**, McGill University Teaching and Learning Services “Learn to Teach Day” full-day training on effective teaching skills, assessment in the social sciences and fostering academic success at the under/graduate level held at McGill University.

#### 6a. Professional Contributions

1. September 11, 2017 **Invited expert** on Canadian research ethics review policy for the Genome Canada Workshop on Rare Diseases in Ottawa (ON).
2. November 28, 2017 **Invited expert** on centralization of research ethics review for the Dawson College Board of Governors Meeting in Montreal (QC).

#### 6b. Memberships in Professional and/or Learned Societies

1. 2017 - present College of Family Physicians of Canada

2. 2017 - present The Canadian Association for Health Services and Policy Research
3. 2016 - present McGill University Science & Policy Exchange
4. 2016 - present International Society of Biological and Environmental Repositories (ISBER)
5. 2015 - present American Association for the Advancement of Science (AAAS)
6. 2015 - present Hellenic Scholarship Federation (HSF)
7. 2015 - present North American Primary Care Research Group (NAPCRG)
8. 2014 - 2016 American College of Medical Genetics (ASHG)
9. 2013- present Canadian Bioethics Society (CBS)
10. 2012 - present American Society of Bioethics and Humanities (ASBH)

## **G. RESEARCH**

### **1. Research Activities**

#### **1a. Current**

##### **Precision medicine and the learning healthcare system**

- to assess the ethical-legal impacts of integrating genomic testing in primary care
- to develop best practices and ethics guidelines for the responsible sharing of genomic and health-related data between the primary care clinic and public health agencies
- to develop professional competencies for primary care and public health trainees at the graduate and postgraduate level

##### **Evidence-based research policy and ethics governance**

- to responsible research governance and oversight of collaborative public health and biomedical research involving humans
- to improve foundational and procedural mechanisms of research ethics review policies in North America that are harmonized with international standards
- to optimize the participation of vulnerable populations in biomedical and public health research
- to enhance graduate training in, and contribute novel methodologies to empirical bioethics and policy analysis with a critical theory and postmodern orientation

## Genomic literacy and bioethical competency

- to develop and evaluate genomics-oriented training for primary care practitioners, nurses, public health agencies, medical students, undergraduate and graduate students
- to foster practitioner competency in bioethics and the medical humanities as a feature of professional identity and responsible practice
- to evaluate the impact of genomics training on primary care delivery and population health outcomes

## 1b. Past

### International development and global health:

- wastewater irrigation biology and health impacts in rural slums (South India)
- participatory action research in municipal water and sanitation policy in rural slums
- youth health education and curriculum development around safe water

## 2. Personal Support Awards

(\*indicates peer reviewed award)

	Term	Award Funding Agency	Amount
1.	March 2018	<b>Best Poster prize—American Association for the Advancement of Science (AAAS)</b> Medicine and Public Health 2018 Annual Meeting, Austin TX (USA)	US\$500
2.	2017 - 2018	<b>Travel Award – Institute for Community Support*</b> CIHR #387839 Governance outside the box: reimagining blockchain as a policy tool to facilitate single institutional review and data sharing in the data-intensive sciences	\$1,000
3.	2017 - 2018	<b>Isaac Tannenbaum Fellowship</b> CLSC Metro Department of Family Medicine, McGill University	\$1,000
4.	2016 - 2017	<b>Travel Award – Institute for Community Support*</b> CIHR #363843 Care to Share? A comparative analysis of data sharing policies in international dementia research	\$1,500
5.	2015 - 2016	<b>Pink in the City Scholarship</b> Hellenic Scholarship Federation	\$2,000
6.	2014 - 2015	<b>Friends of McGill Fellowship</b> McGill University	\$20,000



	<b>Term</b>	<b>Award Funding Agency</b>	<b>Amount</b>
7.	2014 - 2015	<b>Travel Award – Institute Community Support*</b> CIHR #335517 Disclosing Incidental Findings in Pediatrics: Health Professional Perceptions and Insight	\$1,000
8.	2012 - 2014	<b>David McCutcheon Pediatric Palliative Care Fellowship</b> McGill University	\$20,000
9.	2013 - 2014	<b>Travel Award - Institute for Community Support*</b> CIHR #308464 Engaging Children in Research for Self-Reported Quality of Life Outcomes: A review of Established Methods	\$1,000
10.	2008 - 2009	<b>Father Tom Paris Scholarship</b> Ascension Greek Orthodox Cathedral, Oakland CA	USD \$2000
11.	2008 - 2009	<b>Senior Scholarship Award</b> Clayton Business Association, Clayton CA	USD \$2,000

### 3. Peer Reviewed Research Grants

#### 3a. Current

	<b>Term</b>	<b>Project Funding Agency Role</b>	<b>Amount CAD (% attributed)</b>
1.	2018 - 2020	<u>Internal Social Sciences and Humanities Development Grant</u> Types of Referring among Physicians: A Qualitative Study Co-Investigator	\$7,000 (100%)
2.	2017 - 2019	<u>Meeting the demand or gatekeeping the supply? Developing an organizational model of primary care physician referral within family medicine groups in Montreal</u> McGill University Centre for Social and Cultural Data Science (CSCDS) Co-Investigator	\$2,000 (100%)

	<b>Term</b>	<b>Project Funding Agency Role</b>	<b>Amount CAD (% attributed)</b>
3.	2016 - 2019	<u>Evaluating the gap between research ethics review governance and data sharing in the pediatric data-intensive sciences</u> CIHR 359258 Vanier Canada Graduate Scholarship Principal Investigator	\$150,000 (100%)
4.	2015 - 2018	<u>GE3LS Network in Genomics and Personalized Health: Research Ethics Review</u> Genome Canada Coordinator Principal Investigator: B.M. Knoppers	\$240,000 (15%)
5.	2015 - 2019	<u>Can-SHARE</u> Genome Canada, CIHR Academic Secretary Co- Principal Investigators: B.M. Knoppers, M. Brudno, J. Friedman	\$3,300,000 (1%)

### 3b. Past

	<b>Term</b>	<b>Project Funding Agency Role</b>	<b>Amount</b>
1.	2010 - 2011	<u>Haath Mein Sehat (Health in Hands)</u> Big Ideas@Berkeley Blum Centre for Developing Economies Co-applicant PI: Kara Nelson	USD \$18,000 (20%)

## 4. Publications

### 4a. Peer Reviewed Publications

- 2018  
(Forthcoming  
November 2018) **Rahimzadeh V**, Bartlett G, Knoppers BM. Cloudy with a chance of data? Forecasting ethical-legal considerations for sharing pediatric genomic and associated clinical data. Health Affairs.

2. 2018  
(Forthcoming  
November 2018) **Rahimzadeh V**, Knoppers BM, Bartlett G. Responsible genomic and associated clinical data sharing involving children: a systematic review of reasons. JAMA Pediatrics
  
3. 2018  
(Under review) Gagnon J, **Rahimzadeh V**, Longo C, Nugus P, Bartlett G. Including Ethnography in Deliberative Stakeholder Consultations to Evaluate Analytic and Deliberative Outputs: Providing insight for a Pediatric Oncology Genomic Implementation Study. Journal of Health Organization and Management.
  
4. July 2018  
(In press) Bartlett G, Longo C, Puzhko S, Gagnon J, **Rahimzadeh V**. Deliberative Stakeholder Consultations: Removing Researcher Bias for Evidence Implementation in Family Medicine. Family Practice.
  
5. 2018 **Rahimzadeh V**. Precision medicine and instrumentalizing the patient? Letter to the Editor. Annals of Family Medicine.
  
6. 2018 **Rahimzadeh V**. Ethics governance outside the box: reimagining blockchain as a tool to facilitate single ethics review and data sharing for the 'omics' sciences. Blockchain in Healthcare Today 2018, 1(1).
  
7. 2018 **Rahimzadeh V**, Schickhardt C, Knoppers BM, Sénécal K, Vears DF, Fernandez CV, Pfister S, Plon S Clayton EW, Terry S, Williams J, Williams MS, Cornel M, Friedman JM, Pediatric Task Team of the Global Alliance for Genomics and Health. Key Implications of Data Sharing in pediatric genomics: points to consider for **KIDS**. JAMA Pediatrics.
  
8. 2017 **Rahimzadeh V**. The raison d'être of mutual recognition: An analysis of the 2015 reforms to research ethics review policies, processes and problems in Québec. Health Reform Observer 2017, 5(3) doi: <https://doi.org/10.13162/hro-ors.v5i3.2708>.
  
9. 2017 **Rahimzadeh V**, Bartlett G. Policies and practices of data-intensive primary care in the precision-medicine era. Internal Medicine Reviews 2017, 3(9). doi <http://dx.doi.org/10.18103/imr.v3i9.558>
  
10. 2017 **Rahimzadeh V**, Dove ES, Knoppers BM. The sIRB system: a single beacon of progress in the revised Common Rule? American Journal of Bioethics 2017, 17(7):43-46. doi: 10.1080/15265161.2017.1328530.

11. 2016 Isasi R, **Rahimzadeh V**, Charlebois K. Uncertainty and innovation: understanding the role of cell- based manufacturing facilities in shaping regulatory and commercialization environments. Applied & Translational Genomics 2016, 11: 27-39. <http://dx.doi.org/10.1016/j.atg.2016.11.001>
12. 2016 Longo C, **Rahimzadeh V**, O'Doherty K, Bartlett G. Addressing ethical challenges at the intersection of pharmacogenomics and primary care: results of deliberative consultations with patients, physicians, and policy-makers. Pharmacogenomics. doi:10.2217/pgs-2016-0092.
13. 2016 Tassé AM, Bledsoe AM, Giepmans L, **Rahimzadeh V**. Legal and ethical implications of data sharing in international biobank research: towards a global response. Biopreservation and Biobanking 2016, 14(3):193-194. doi:10.1089/bio.2016.29003.amt.
14. 2016 **Rahimzadeh V**, Dyke SOM, Knoppers BM. International framework for data sharing: moving forward with the Global Alliance for Genomics and Health. Biopreservation and Biobanking 2016,14(3):256-9. doi: 10.1089/bio.2016.0005.
15. 2016 **Rahimzadeh V**, Knoppers BM. How mutually recognizable is mutual recognition in research ethics review? An international terminology index. Personalized Medicine 2016;13(2):101-105. doi: 10.2217/pme.15.52.
16. 2015 Sénécal K, **Rahimzadeh V**, Knoppers BM, Fernandez CV, Avard D, Sinnett D. Statement of principles on the return of research results and incidental findings in paediatric research: a multi-site consultative process. Genome 2015;58(12):541-548. doi: 10.1139/gen-2015-0092.
17. 2015 **Rahimzadeh V**, Bartlett G, Longo C, Crimi C, Macdonald ME, Jabado N, Ells C. Promoting an ethic of engagement in pediatric palliative care research. BMC Palliative Care 2015;14(50). doi:10.1186/s12904-015-0048-
18. 2015 **Rahimzadeh V**. Phasing out voluntary donation in clinical trials: the ethics of mandated biospecimen donation. Journal of Clinical Trials 2015(5):5. doi: <http://dx.doi.org/10.4172/2167-0870.1000241>
19. 2015 Zawati MH, Junker A, Knoppers BM, **Rahimzadeh V**. Streamlining review of research involving humans: Canadian models. Journal of Medical Genetics 2015;52(8):566-9. doi: 10.1136/jmedgenet-2014-102640.

20. 2015 **Rahimzadeh V**, Nugus P, Lessard D. Teaching the sum while paying attention to the parts: whole person care through ethnography in medical education. International Journal of Whole Person Care 2015;2(2):1-5.
21. 2015 **Rahimzadeh V**. A missed opportunity for shared responsibility in adolescent contraception,” Journal of Adolescent & Family Health 2015;7(1). doi: <http://scholar.utc.edu/jafh/vol7/iss1/1>
22. 2014 **Rahimzadeh V**, Bartlett GB. Genetics and primary care: where are we headed? Journal of Translation Medicine 2014; 12(238). doi: 10.1186/s12967-014-0238-6.
23. 2014 **Rahimzadeh V**, Denise Avar, Karine Sénécal, Knoppers BM, Sinnett D. To disclose or not to disclose? Context matters. European Journal of Human Genetics 2014;23(3):279-84. doi: 10.1038/ejhg.2014.108.
24. 2014 Bartlett G, **Rahimzadeh V**, Longo C, Orlando LA, Dawes M, Lachaine J, Bochud M, Paccaud F, Bergman H, Crimi L, Issa AM. The future of genomic testing in primary care: the changing face of personalized medicine. Personalized Medicine 2014;11(5):477-486.  
<https://doi.org/10.2217/pme.14.36>

#### 4b. Technical Reports

1. 2018 Tri-Agency Research Data Management Policy. Standing Committee on Ethics Working group, Canadian Institutes of Health Research.
2. 2016 Ethics Review Mutual Recognition Policy. Ethics Review Equivalency Task Team of the Global Alliance for Genomics and Health. Available from:  
[https://genomicsandhealth.org/files/public/GA4GH%20Ethics%20Review%20Recognition%20Policy\\_FINAL\\_0.pdf](https://genomicsandhealth.org/files/public/GA4GH%20Ethics%20Review%20Recognition%20Policy_FINAL_0.pdf)
3. 2014 Rockman-Greenberg, C., Avar, D., Hanvey, L., Marcotte, M., & Fitzpatrick, J. Genetics and paediatric health: Section 3: Genetic Services. In The Health of Canada’s Children and Youth: A CICH Profile. 2014. Available from:  
<http://profile.cich.ca/en/index.php/chapter2>.
4. 2014 Bartlett G, Longo C, **Rahimzadeh V**, Crimi L. iChange: Ethics and Methods for Engagement in Genomic Research with Vulnerable Populations. Preliminary GE<sup>3</sup>LS Report submitted to the Research Oversight Committee for the Genome Canada Project “the Study of Biomarkers for

#### 4c. Reviews, Book Chapters, Books

1. July 2018  
(In Press) **Rahimzadeh V**, Bartlett G, Longo C, Illes J. Role playing games to facilitate research engagement among youth with neurodevelopment disorders. In: *Global Mental Health and Neuroethics*, edited by Dan Stein.
2. 2017 **Rahimzadeh V**, Tasse AM, Ouelette S. International biobank networks: the P3G experience (2015). In: Hainaut P, Vaught J, Pasterk M, Zatloukal K (eds). Biobanking of Human Biospecimens: Principles and Practices. Springer. New York, NY. ISBN 978-3-319-55120-3.
3. 2017 **Rahimzadeh V**, Sénécal K, Kleiderman E, Knoppers BM (2017). Minors and aged persons living with dementia: ethical intersectionalities for data sharing policy in the data-intensive sciences. In: Illes, J (ed.) *Neuroethics*, Second edition. ISBN: 0-19-8567219.
4. 2016 **Rahimzadeh, V**. Sharing outside the sandbox? A child’s right to an open future for data sharing. In: Verma M, Barh D (eds). Progress and Challenges in Precision Medicine. Elsevier: Academic Press. ISBN 978-0-12809-411-2.
5. 2015 **Rahimzadeh, V**. An ethic of connectedness: Review of the Connected Self: the ethics and governance of the genetic individual. BioéthiqueOnline 2015; 3(7).
6. 2014 **Rahimzadeh V**, Knoppers BM, Joly Y (2015). Bioethics and the law. In: Knoppers BM, Joly Y (eds.). *Handbook of Medical Law and Ethics*. Routledge Publishing. ISBN-13: 978-0415628181.

#### 4d. Abstracts and Conference Presentations

(\*oral presentation, † poster presentation)

1. 2019 **Rahimzadeh V\***. Genomics and the data sharing frontier. Annual Meeting of the American Association for the Advancement of Science (AAAS). Washington, DC (USA) February 14-17.

2. 2018 **Rahimzadeh V\***, Bartlett G, Knoppers BM. Forecasting ethical-legal priorities in genomic and associated clinical data sharing involving children: a policy Delphi study. Wiet Life Science Law Scholars Conference. Chicago, IL (USA) September 7, 2018.
  
3. 2018 Gagnon J, **Rahimzadeh V**, Longo C, Nugus P, Bartlett G†. How professional cultures impact implementation for a pediatric oncology genomic test: the use of ethnographic participant observation in deliberative stakeholder consultations. Organizational Behaviour in Health Care Conference. Montreal, QC (CA) May 15, 2018. [**Highly Commended Paper Award**]
  
4. 2018 **Rahimzadeh V\***. When a #researcher #recruits you over #socialmedia. Innovations and Challenges in Recruiting Children with Neurodevelopmental Disorders in research. Joint workshop with Neuroethics Canada and Kids Brain Health Network. University of British Columbia. Vancouver, BC (CA) February 21, 2018.
  
5. 2018 **Rahimzadeh V†**, Bartlett G. Teaching the blockchain to facilitate learning primary healthcare systems. Annual Meeting of the American Association for the Advancement of Science (AAAS). Austin, TX (USA) February 15-18, 2018. Submitted. [**Best Poster Prize in Medicine and Public Health**]
  
6. 2018 **Rahimzadeh V†**. Genetic/genomic data sharing via the blockchain: a ledger of promise? ATGC Seminar. Genome Quebec Innovation Centre. Montreal, QC (CA) January 18, 2018.
  
7. 2017 **Rahimzadeh V\***. Chain blockers or block chainers? ethically responsible sharing of primary health care data using the blockchain. “Research Games” 3-minute thesis competition. 45th Annual North American Primary Care Research Group Meeting. November 19, 2017.
  
8. 2017 **Rahimzadeh V†**, Knoppers BM, Bartlett G. Validating Points to Consider for KIDS: Key implications of data sharing in pediatric genomics. 45th Annual North American Primary Care Research Group Meeting. Montreal, Canada. November 17-21, 2017.
  
9. 2017 Carver T, Bartlett G, **Rahimzadeh V**, Rodriguez C. Zoom me in! Evaluating an innovative approach to graduate medical education in family medicine research. 45th Annual North American Primary Care Research Group Meeting. Montreal, Canada. November 17-21, 2017.

10. 2017 **Rahimzadeh V\***. Breaking the mold: flourishing multicenter trials in Canada. Invited plenary during the CellCan workshop. Canadian Stem Cell Network. Mont-Tremblant, QC November 6-8, 2017.
11. 2017 **Rahimzadeh V\***, Townend D, Dove ES and the Ethics Review Equivalency Task Team of the Global Alliance for Genomics and Health. Practical guidance for ethics review mutual recognition. 5<sup>th</sup> Plenary of the Global Alliance for Genomics and Health. Orlando, FL (USA) October 15, 2017.
12. 2017 **Rahimzadeh V\***, Friedman J, Cornel M and the Pediatric Task Team of the Global Alliance for Genomics and Health. Key Implications of Data Sharing (KIDS) in pediatric genomics: policy points to consider. 5<sup>th</sup> Plenary of the Global Alliance for Genomics and Health in Orlando, FL (USA). October 15, 2017.
13. 2017 **Rahimzadeh V†**, Knoppers BM. Chained to the block or saved by it? Re-imagining blockchain to facilitate mutual recognition in research ethics governance for the data intensive sciences. Global Biobank Week, Stockholm, Sweden. September 14, 2017.
14. 2017 **Rahimzadeh V\***, Knoppers BM. Governance outside the box: reimagining blockchain as a policy tool to facilitate single institutional review and data sharing in the data-intensive sciences. Wiet Life Science Scholars Conference. Loyola University of Chicago Law in Chicago, IL (USA). October 13, 2017.
15. 2017 **Rahimzadeh V\***, Bartlett G, Knoppers BM. Link. Share. Cure. A systematic mapping review of ethical, legal and social considerations for sharing genomic and health-related data involving children. Canadian Bioethics Society Annual Conference. Montreal, QC (CA), May 26, 2017. [Accepted]
16. 2017 **Rahimzadeh, V\***. Tool building for research ethics mutual recognition. ISBER Annual Meeting in Toronto, ON (CA). May 9-12, 2017.
17. 2017 **Rahimzadeh, V\***. Policy relevant truth telling in ethics governance of the data-intensive sciences: a tale of two(?) narratives. Invited workshop plenary, Annual Meeting of the Canadian College of Medical Geneticists in Montreal, QC (CA). May 3, 2017.



18. 2017 **Rahimzadeh, V\***. Sharing outside the sandbox: Phase I of a policy delphi study to develop an ethical framework for sharing genomic research and clinical data involving children. UNESCO Chair in Bioethics. Limassol, Cyprus. March 21-23, 2017.
19. 2017 **Rahimzadeh V†**, Bartlett G, Knoppers BM. Key implications of data sharing in pediatric genomics and clinical care. Meeting of the American Association for the Advancement of Science (AAAS) in Boston, MA (USA), February 15-19, 2017.
20. 2016 **Rahimzadeh V†**, C. Schickhardt, J. Friedman, M.C. Cornel, S. Pfister, D. Avard, D.F. Vears, K. Sénécal, W. Pinxten, C. Fernandez, S. Plon, A. Thorogood, B.M. Knoppers, E. Winkler. Ethics policy points to consider for KIDS: Key Implications of Data Sharing in pediatric genomics and clinical care. BioConnect McGill in Montreal, QC (CA), November 18, 2016.
21. 2016 Mamishi N, Carver T, Rosenberg E, Issa A, Macgibbon B, **Rahimzadeh V**, Bartlett G. Barriers and Facilitators to Breast Cancer Screening: A Quantitative Study Among Iranian Immigrant Women in Montreal. 44<sup>th</sup> Annual North American Primary Care Research Group Meeting in Colorado Springs, CO (USA), November 13-17, 2016.
22. 2016 **Rahimzadeh, V†**; C. Schickhardt, J. Friedman, M.C. Cornel, S. Pfister, D. Avard, D.F. Vears, K. Sénécal, W. Pinxten, C. Fernandez, S. Plon, A. Thorogood, B.M. Knoppers, E. Winkler. The sharing of genomics and health-related data from children: A case of big data and little ethics? Annual Meeting of the American Society of Human Genetics in Vancouver, BC (CA), October 18-21, 2016.
23. 2016 **Rahimzadeh V\***, Martin Bobrow, Anna Petaja Leinonen. Ageing and Dementia Task Team Annual Report". 4<sup>th</sup> Plenary Meeting of the Global Alliance for Genomics and Health in Vancouver, BC (CA), October 16, 2016.
24. 2016 **Rahimzadeh V\***, Martin Bobrow, Anna Petaja Leinonen. Moving forward with the Ageing and Dementia Task Team of the Global Alliance for Genomics and Health. Panel on Neuroimaging ethics. 4<sup>th</sup> Plenary of the Global Alliance for Genomics and Health in Vancouver, BC (CA), October 17, 2016.
25. 2016 Bartlett G, Longo C, **Rahimzadeh V**, Gagnon J, Puzhko S. Deliberative Stakeholder Consultations: A Method for Engagement and Knowledge Translation. PriFor 2016 - How We Know What We Know. St. Johns, Newfoundland.

26. 2016 **Rahimzadeh V†**, Knoppers BM. The principle of mutual recognition and research ethics review in the era of personalized medicine: a model policy. First International Congress on Personalized Health Care in Montreal, QC (CA), June 12-15, 2016.
27. 2016 Knoppers BM, **Rahimzadeh V\***. The GE3LS that Bind: Moving forward with the Precision Medicine Policy Network. First International Congress on Personalized Health Care in Montreal, QC (CA), June 12-15, 2016.
28. 2016 **Rahimzadeh V\***, Knoppers BM, Ravitsky V, Morin K, Pullman D, Bond W, Junker A, Zawati MH, Joly Y. Taking a provincial, national and international pulse of research ethics review 'reciprocity' workshop. Canadian Bioethics Society Annual Conference /Canadian Association of Research Ethics Boards. Toronto, ON. May 25-28, 2016.
29. 2016 **Rahimzadeh V†**, Knoppers BM, Mäki-Petäjä-Leinonen A, Bobrow M. "Care to Share? A comparative analysis of data sharing policies involving research with decisionally-incompetent adults with dementia." International Congress of Human Genetics. Kyoto, Japan. April 3-7, 2016. [Declined].
30. 2016 **Rahimzadeh V\***. The status of ethics review mutual recognition in Canada. Second Meeting of the Ethics Review Equivalency Task Team for the Global Alliance of Genomics and Health. Montreal, QC (CA) May 2-3, 2016.
31. 2016 **Rahimzadeh V\***. Data sharing and the Global Alliance for Genomics and Health. Webinar. Connected Open Research Ethics. University of California San Diego, San Diego CA (USA). February 23, 2016.
32. 2015 **Rahimzadeh, V\***. Canadian Academy of Health Sciences Annual Meeting. Ottawa, ON. September 16-18, 2015.
33. 2015 **Rahimzadeh, V\***. Promoting an Ethic of Engagement. 11th Annual Pediatric Bioethics Conference. Seattle, WA (USA). July 24-25, 2015. [Student abstract scholarship winner].
34. 2015 **Rahimzadeh V†**, Bartlett G, Knoppers BM. Comparative health policy analysis of research ethics review governance across Canada. Canadian Bioethics Society Annual Conference. Winnipeg, MB (CA). May 27-29 2015.
35. 2015 **Rahimzadeh V†**, Bartlett G, Knoppers BM. Research ethics review of 'Big Data' in Canada. Canadian GE3LS and Health Services and Policy Research Conference Vancouver, BC (CA). April 18-21, 2015.

36. 2015 **Rahimzadeh, V\***. The Road to Reciprocity: Research Ethics Review and Governance in the Post Genomic Era. McGill Family Medicine Research Division and Graduate Student Society Symposium. Montreal, QC (CA). February 18, 2015.
37. 2015 **Rahimzadeh V\***, Sénécal K, Avard D, Knoppers BM. Disclosing Incidental Findings in Pediatrics: Perceptions and Insights for Health Professionals. UNESCO Bioethics Chair 10<sup>th</sup> World Conference. Jerusalem, Israel. January 6 - 8, 2015.
38. 2014 Bartlett G, Longo C, **Rahimzadeh V**, Crimi L. New Methods to Engage Children in Health Care Research: The Case of Health Related Quality of Life (HRQoL). North American Primary Care Research Group Annual Meeting. New York, NY (USA). November 21- 24, 2014.
39. 2014 Bartlett G, Longo C, **Rahimzadeh V**, Crimi L. New Methods to Engage Children in Health Care Research: The Case of Health Related Quality of Life (HRQoL). 42nd North American Primary Care Research Group Annual Meeting. New York, New York.
40. 2014 **Rahimzadeh V\***. Return of Incidental Findings in Pediatric Oncology. European Society of Human Genetics Annual Conference. Milan, Italy. May 30, 2014.
41. 2014 **Rahimzadeh, V\***. To Disclose, or Not to Disclose? The Context Matters. Canadian Bioethics Society Annual Conference. Vancouver, British Columbia (CA). May 29, 2014.
42. 2014 **Rahimzadeh V\***. On the Ethics of Engagement: Health-Related Quality of Life for Terminally Ill Children and Adolescents. Canadian Bioethics Society Annual Conference. Vancouver, British Columbia (CA). May 28, 2014.
43. 2014 **Rahimzadeh V†**, Sénécal K, Avard D, Knoppers BM. From Bench to Bedside to Policy: Perceptions of Investigators on the Return of Incidental Findings in Paediatric Oncology. Canadian Bioethics Society Annual Conference. Vancouver, British Columbia (CA) May 28, 2014.
44. 2014 Zawati MH, **Rahimzadeh V**, Knoppers BM. Proposed Changes to Guidelines for Incidental Findings in TCPS2. RMGA Journee Genetique. Montreal, QC (CA). May 16, 2014.
45. 2014 **Rahimzadeh V\***. Adolescents and Cancer Diagnosis. Fourth Biennial Bilingual Canadian Society for the Sociology of Health Conference. Montreal, Quebec (CA). May 6, 2014.
46. 2013 **Rahimzadeh V†**. Achieving Personalization in Genomic

Medicine and Whole Person Care. First International Congress on Whole Person Care. Montreal, QC (CA). October 18, 2013.

47. 2013

**Rahimzadeh V\***. Ethics of Integrating Genomic Medicine and Primary Care. Annual Meeting of the American Society of Bioethics and Humanities. Hilton, Atlanta, GA (USA). October 26, 2013.

## 5. Referees

1. Professor Bartha Maria Knoppers  
Phd, FRSC, FCAHS

**Director, Centre of Genomics and Policy**  
Canada Research Chair in Law and Medicine  
[Phd Co-supervisor]  
740 Ave Dr Penfield Suite 5200  
Montreal, QC H3A-0G1  
Email: [Bartha.knoppers@mcgill.ca](mailto:Bartha.knoppers@mcgill.ca)  
Tel: 514.398.8155  
Fax: 514.398.8954
2. Professor Gillian Bartlett-Esquilant

**Associate Chair, Research and Graduate Program Director**  
Department of Family Medicine  
5858 Côte-des-Neiges, Suite 300  
Montreal, QC H3S 1Z1  
Email: [gillian.bartlett@mcgill.ca](mailto:gillian.bartlett@mcgill.ca)  
Tel: (514) 399-9109
3. Eugene Bereza  
MD, CM, CCFP

**Director, Centre for Applied Ethics**  
McGill University Health Centre  
2155 Guy St, 2<sup>nd</sup> floor Room 321  
Montreal, QC H3H-2R9  
Email: [eugene.bereza@mcgill.ca](mailto:eugene.bereza@mcgill.ca)  
Tel: 514.934.1934 ext: 34323
4. David Winickoff, PhD

**Senior Policy Analyst**  
Secretariat Working Party  
Organization for Economic Co-operation and Development  
2, rue André Pascal  
75775 Paris Cedex 16  
France  
Email: [david.winickoff@oecd.org](mailto:david.winickoff@oecd.org)
5. Eric Meslin  
PhD, FCAHS

**President and CEO**  
Council of Canadian Academies  
Email: [eric.meslin@scienceadvice.ca](mailto:eric.meslin@scienceadvice.ca)  
Tel: 613.567.5000 ext. 236