

Vasiliki Nataly Rahimzadeh, PhD

Curriculum Vitae

September 2019

Table of Contents

A. IDENTIFICATION	3
B. EDUCATION	3
1. Degrees	3
2. Theses/Dissertations.....	3
C. APPOINTMENTS	4
1. National Appointments.....	4
2. Research Appointments	4
3. Other Appointments.....	4
D. SPECIAL HONOURS, AWARDS, RECOGNITION	4
E. TEACHING	5
1. McGill University	5
1a. Undergraduate.....	5
1b. Graduate.....	5
1c. Graduate Program Development.....	6
2. University of California Berkeley	6
2a. Undergraduate.....	6
3. Trainee Supervision	6
3a. Master of Science Trainees.....	6
3b. Juris Doctor Candidate Mentoring.....	6
3c. Graduate Student Mentoring.....	7
4. Invited Presentations, Lectures and Seminars	7
14. Program Development Activities.....	9
F. ADMINISTRATION/SERVICE	9
1. Journals.....	9
1a. International Editorial Boards.....	9
1b. Ad hoc Reviews.....	9
1c. Journal Editing.....	9
3. Conferences.....	10
3a. Abstract/Paper Reviews for International Conference.....	10
3b. Conference Activities.....	10
International	10
National.....	11
McGill University.....	11
4. Administrative Responsibilities.....	11
5. Committees	12
5a. McGill University and greater Montreal	12
5b. National	12
5. Professional Development	12
6a. Professional Contributions	13
6b. Memberships in Professional and/or Learned Societies.....	14
G. RESEARCH	14
1. Research Activities	14
1a. Current.....	14
1b. Past.....	15
2. Personal Support Awards and Honors	15
3. Peer Reviewed Research Grants.....	17
3a. Current.....	17
3b. Past.....	17
4. Publications	18

4a. Peer Reviewed Publications	18
4b. Technical Reports	21
4c. Reviews, Book Chapters, Books	21
4d. Abstracts and Conference Presentations.....	22
5. Media Coverage.....	29
6. Referees.....	29

Common Acronyms:

CIHR: Canadian Institutes for Health Research

MUHC: McGill University Health Center

GA4GH: Global Alliance for Genomics and Health

GC: Genome Canada

GQ: Genome Quebec

NIH: National Institutes of Health

SCE: Standing Committee on Ethics

A. IDENTIFICATION

Name Vasiliki Nataly Rahimzadeh

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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. Degrees

University	Degree	Subject Area	Dates
University of California Berkeley	BS	Microbial Biology	2012
McGill University	MSc	Experimental Medicine [Biomedical Ethics specialization]	2014
McGill University	PhD	Family Medicine and Primary Care Research, [Biomedical Ethics specialization]	2019

2. Theses/Dissertations

	Title	Supervisors	Funding
MSc	On the ethics of engagement: health-related quality of life in terminally ill children and adolescents	Carolyn Ells Biomedical Ethics Unit, McGill University Gillian Bartlett Department of Family Medicine, McGill University	David McCutcheon Paediatric Palliative Care Fellowship

PhD Evaluating the gap between research ethics review and data sharing in the pediatric infrastructure sciences: a case of big data and little ethics?

Bartha Maria Knoppers,
Centre of Genomics and Policy,
McGill University
Gillian Bartlett
Department of Family
Medicine, McGill University

Vanier Canada
Graduate
Scholarship
(CIHR#359258)

C. APPOINTMENTS

1. National Appointments

2017 – 2020 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 **Admitted** to the Golden Key Graduate Honour Society
McGill University

2010 **Sys Collins Service and Membership Award**
Chi Omega Mu Chapter, University of California Berkeley

E. TEACHING

1. McGill University

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- 2018 Thesis Committee Member for Nina Mamishi
Family Medicine
Thesis: Barriers and Facilitators to Breast Cancer Screening: A Quantitative Study among Iranian Immigrant Women in Montreal

3b. Juris Doctor Candidate Mentoring

2. 2017 - 2018 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*

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. 2016 Nadia Sourial, PhD Candidate (2017 Vanier recipient)
Vanier Canada Graduate Scholarship application mentor
Department of Family Medicine, McGill University
3. 2016 Ayat Salman, PhD Candidate
Vanier Canada Graduate Scholarship application mentor
Department of Family Medicine, McGill University
4. 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
Applicquée 2014 Gérard – Bouchard
Fellowship

4. Invited Presentations, Lectures and Seminars

1. July 29, 2019 **Keynote**—National Cancer Institute Childhood Cancer Data Initiative—Pediatric data sharing in the oncological infrastructure sciences: the golden rule for ethics governance? in Washington D.C. (USA)
2. May 1, 2019 **Grand Rounds**—Children and the genomics-enabled health system: a case of big data and little ethics? St. Mary’s Hospital in Montreal, QC. (CA)
3. April 3, 2019 **Seminar**—Data sharing: the contemporary bioethics golden rule? McGill University, Department of Family Medicine Research Seminar in Montreal, QC (CA)

4. March 25, 2019 **Panelist**—International collaboration for quality results - samples from biobanks as pacemaker for a better medicine. International Biobanking Conference, Doha, Qatar.
5. Jan 4-10, 2019 **Workshop**—Translating ideas to action for responsible innovation. 2019 Winter School, hosted by the Arizona State University School for the Future of Innovation in Society in Phoenix, AZ (USA).
6. Dec 5, 2018 **Guest Lecture**—Ethics in qualitative health research McGill University Department of Family Medicine, FMED625 Qualitative Research Methods in Health in Montreal, QC (CA)
7. July 3, 2018 **Invited expert**—Genomic Security with EncrypGen Gene-chain and the DNA Token. Blockchain in Healthcare Webinar Series.
8. Feb 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>
9. Feb 21, 2018 **Workshop**—Innovations and Challenges in Recruiting Children with Neurodevelopmental Disorders in Research. National Core for Neuroethics, University of British Columbia, Vancouver BC (CA)
10. Oct 23, 2017 **Guest Lecture**—Ethics in qualitative health research McGill University Department of Family Medicine, FMED625 Qualitative Research Methods in Health in Montreal, QC (CA)
11. May 5, 2017 **Invited plenary**—Policy relevant truth telling in ethics governance of the data-intensive sciences: a tale of two(?) narratives. Annual Meeting of the Canadian College of Medical Geneticists in Montreal, QC (CA).
12. May 12, 2016 **Invited plenary**—Evaluating the gap between research data sharing and ethics governance in the pediatric data intensive sciences. McGill University Department of Family Medicine, Annual Research Symposium Vanier Scholarship Award recipient address in Montreal, QC (CA)
13. Oct 24, 2015 **Guest lecture**—Ethics in qualitative health research McGill University Department of Family Medicine, FMED625 Qualitative Research Methods in Health in Montreal, QC (CA)

14. Program Development Activities

- i.1. 2016 - present Content curator and module developer for online resident training on 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)
6. 2019 – present Medical Journal of Australia (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

3. Conferences

3a. Abstract/Paper Reviews for International Conference

1. 2015 – present Canadian Bioethics Society Annual Meeting (16 abstracts)

3b. Conference Activities

International

1. 2018 **Course volunteer** for the satellite meeting of the Grants Generating Program sponsored by the North American Primary Care Research Group. Chicago, IL (USA) November 9, 2018.
2. 2018 **Workshop and satellite meeting co-organizer** for the Regulatory and Ethics Work Stream of the Global Alliance for Genomics and Health: “Vulnerability policy for international data sharing” at the 6th Plenary of the Global Alliance for Genomics and Health held in Basel, Switzerland. October 3-5, 2018.
3. 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 5th Plenary of the Global Alliance for Genomics and Health held in Orlando, FL. October 15-17, 2017.
4. 2017 **Panel organizer and session moderator** at the UNESCO Chair in Bioethics 12th World Conference on Bioethics, Medical Ethics and Health Law: “Genetics and Ethics”, Limassol (Cyprus)
5. 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 5th Plenary of the Global Alliance for Genomics and Health held in Orlando, FL.
6. 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.

7. 2015 **Panel organizer and session moderator** at the UNESCO Chair in Bioethics 10th 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 4th 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 – 2019 **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. 2018 – present **Member**, Special Interest group on ethics in the learning healthcare system. CIHR Standing Committee on Ethics, Rafael Saginur (Chair).
2. 2014 – present **Member**, Maternal Infant Child Youth Network (MICYRN)

5. 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- 25th 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 3rd Annual Winter School: “Anticipatory governance, responsible innovation and social studies on emerging technologies.” Tempe AZ (USA) January 3 - 10, 2016.
8. 2015 **Attendee**—Canadian Academy of Health Sciences Annual Meeting. Ottawa, ON. September 16-18, 2015
9. 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.
10. 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 2019 **Invited expert**—Academic Bioethics Advisor/Lead, Coalition Against Childhood Cancer (CAC2) Ethics Working Group.

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

6b. Memberships in Professional and/or Learned Societies

1. 2018 - present American Medical Informatics Association
2. 2017 - present College of Family Physicians of Canada
3. 2017 - present The Canadian Association for Health Services and Policy Research
4. 2016 - present McGill University Science & Policy Exchange
5. 2016 - present International Society of Biological and Environmental Repositories (ISBER)
6. 2015 - present American Association for the Advancement of Science (AAAS)
7. 2015 - present Hellenic Scholarship Federation (HSF)
8. 2015 - present North American Primary Care Research Group (NAPCRG)
9. 2014 - 2016 American College of Medical Genetics (ASHG)
10. 2013- present Canadian Bioethics Society (CBS)
11. 2012 - present American Society of Bioethics and Humanities (ASBH)

G. RESEARCH

1. Research Activities

1a. Current

Precision medicine, big data and the learning healthcare system

- to assess the ethical-legal infrastructures required to operationalize genomics-enabled learning health systems
- to develop best practices, data standards and ethics guidelines in partnership with patients for the responsible sharing of their genomic and associated clinical data

- to ensure the technical integration of genomic data into the electronic medical record is compliant with local, national and international data protection norms

Evidence-based research policy and ethics governance

- to facilitate responsible research governance and oversight of collaborative public health and biomedical research involving humans
- to improve foundational and procedural mechanisms of single research ethics review policies in North America and 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 the field of empirical bioethics as well as critical policy analysis

Genomic literacy and bioethical competency

- to develop and evaluate genomics-oriented training for healthcare practitioners, 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 clinical practice
- to evaluate the impact of genomics training on healthcare 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 and Honors

(*indicates peer reviewed award)

	Term	Award Funding Agency	Amount
1.	June 2019	CIHR Student Research Forum* —National dissertation poster competition finalist	CAD\$1000
2.	February 2019	MedStar Award* — Faculty of Medicine, McGill University In recognition of excellence in medical publishing by a graduate trainee at McGill University	CAD\$500
3.	February 2019	Travel Fellowship* — Network of Applied Medical Genetics	CAD\$1500
4.	March 2018	Best Poster prize — American Association for the Advancement of Science (AAAS) Medicine and Public Health category 2018 Annual Meeting, Austin TX (USA)	US\$500

	Term	Award Funding Agency	Amount
5.	2017 - 2018	Travel Award – Institute for Community Support* 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	CAD\$1,000
6.	2017 - 2018	Isaac Tannenbaum Fellowship CLSC Metro, Montreal QC Department of Family Medicine, McGill University	CAD\$1,000
7.	2016 - 2017	Travel Award – Institute for Community Support* CIHR #363843 Care to Share? A comparative analysis of data sharing policies in international dementia research	CAD\$1,500
8.	2015 - 2016	Pink in the City Scholarship Hellenic Scholarship Federation	CAD\$2,000
9.	2014 - 2015	Friends of McGill Fellowship McGill University (declined)	CAD \$20,000
10.	2014 - 2015	Travel Award – Institute Community Support* CIHR #335517 Disclosing Incidental Findings in Pediatrics: Health Professional Perceptions and Insight	CAD\$1,000
11.	2012 - 2014	David McCutcheon Pediatric Palliative Care Fellowship McGill University	CAD \$20,000
12.	2013 - 2014	Travel Award - Institute for Community Support* CIHR #308464 Engaging Children in Research for Self-Reported Quality of Life Outcomes: A review of Established Methods	CAD\$1,000
13.	2008 - 2009	Father Tom Paris Scholarship Ascension Greek Orthodox Cathedral, Oakland CA	USD\$2000
14.	2008 - 2009	Senior Scholarship Award Clayton Business Association, Clayton CA	USD\$2,000

3. Peer Reviewed Research Grants

3a. Current

	Term	Project Funding Agency Role	Amount (% attributed)
1.	2018 - 2020	<u>Internal Social Sciences and Humanities Development Grant</u> Types of Referring among Physicians: A Qualitative Study Co-Investigator	CAD\$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	CAD\$2,000 (100%)
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	CAD \$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	CAD\$240,00 0 (15%)
5.	2015 - 2019	<u>Can-SHARE</u> Genome Canada, CIHR Academic Secretary Co- Principal Investigators: B.M. Knoppers, M. Brudno, J. Friedman	CAD \$3,300,000 (1%)

3b. Past

	Term	Project Funding Agency Role	Amount
1.	2010 - 2011	<u>Haath Mein Sehat (Health in Hands)</u> Big Ideas@Berkeley	USD \$18,000

Term	Project Funding Agency Role	Amount
	Blum Centre for Developing Economies Co-applicant PI: Kara Nelson	(20%)

4. Publications

4a. Peer Reviewed Publications

1. 2019
(Submitted) **Rahimzadeh V**, Bartlett G, Knoppers BM. Cloudy with a chance of data? Forecasting ethical-legal considerations for sharing pediatric genomic and associated clinical data. British Medical Journal.
2. 2019
(Under review) **Rahimzadeh V**, Knoppers BM, Bartlett G. Responsible genomic and associated clinical data sharing involving children: a systematic review of reasons. American Journal of Bioethics.
3. 2019
Illes, J, Antle A, Lou H, Longstaff H, **Rahimzadeh V**, mcdonald P.J, Van der Loos HFM, Kids Brain Health Network Working Group on Involving Children with Neurodevelopmental Disorders in Research. Reflections involving children with neurodevelopmental disorders in biomedical research. Lancet Child and Adolescent Health.
4. 2018
Granados Moreno P, Ali-Khan SE, Capps B, Caulfield T, Chalaud D, Edwards A, Gold ER, **Rahimzadeh V**, Thorogood A, Auld D, Bertier G, Bonter L, Breden F, Caron R, Cesar P, Cook-Deegan R, De Luca C, Doerr M, Duncan R, Issa AM, Reichman J, Simard J, So D, Vanamala S, Joly J. Open-Science Precision Medicine in Canada: Points to Consider. FACETS.
5. 2018
Bartlett G, Longo C, Puzhko S, Gagnon J, **Rahimzadeh V**. Deliberative Stakeholder Consultations: Removing Researcher Bias for Evidence Implementation in Family Medicine. Family Practice.
6. 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.

7. 2018 **Rahimzadeh V.** Precision medicine and instrumentalizing the patient? Letter to the Editor. Annals of Family Medicine.
8. 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).
9. 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.
10. 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/hros.v5i3.2708>.
11. 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>
12. 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.
13. 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>
14. 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.

15. 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.
16. 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.
17. 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.
18. 2015 Sénécal K, **Rahimzadeh V**, Knoppers BM, Fernandez CV, Avard D, Sinnott 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.
19. 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-
20. 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>
21. 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.
22. 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.
23. 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>.

24. 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.
25. 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.
26. 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
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 GE³LS Report submitted to the Research Oversight Committee for the Genome Canada Project “the Study of Biomarkers for Pediatric Glioblastoma through Genomics and Epigenomics.”

4c. Reviews, Book Chapters, Books

1. March 2020 (Forthcoming) **Rahimzadeh V**. Digital governance for learning health systems: Promises and Problems. In: Liaw, T (ed.) *Routledge Handbook of Fintech*.

2. July 2019
(In Press) **Rahimzadeh V**, Bartlett G, Longo C, Illes J. Role playing games to facilitate research engagement among youth with neurodevelopment disorders. In: Stein, D (ed). *Global Mental Health and Neuroethics*.
3. 2017 **Rahimzadeh V**, Tasse AM, Ouelette S. International biobank networks: the P3G experience. 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.
4. 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.
5. 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.
6. 2015 **Rahimzadeh, V**. An ethic of connectedness: Review of the Connected Self: the ethics and governance of the genetic individual. BioéthiqueOnline 2015; 3(7).
7. 2015 **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. 2020 **Rahimzadeh V***. The ethics of learning health systems. Stanford Center for Biomedical Ethics Seminar Series. Stanford, CA, January 21, 2020.
2. 2020 **Rahimzadeh V***. Data Ethics. Stanford Center for Biomedical Ethics Seminar Series. Stanford, CA, January 21, 2020.
3. 2019 Bartlett G, Longo C, Issa A, **Rahimzadeh V***. Anthony's Game: When Direct Questions Do Not Work in Assessing Young People's Treatment Preferences. North American Primary Care Research Group, Toronto (CA), November

16-20, 2019.

4. 2019 **Rahimzadeh, V***. Data sharing: on the ethical frontlines of collaboration. National Cancer Institute Childhood Cancer Data Initiative Symposium, Washington DC (USA). July 29-31, 2019.
5. 2019 **Rahimzadeh V[†]**, Bartlett G, Knoppers BM. Evaluating the gap between research ethics review and data sharing in the pediatric infrastructure sciences: a case of big data and little ethics? Canadian Institutes of Health Research Student Research Symposium. Health Sciences Campus, Winnipeg, MB, June 11-14th, 2019. [**Nominated by McGill University as top 5% doctoral candidates**]
6. 2019 **Rahimzadeh V[†]**, Bartlett G, Knoppers BM. Validating the Key Implications of Data Sharing (KIDS) framework for the pediatric infrastructure sciences in Canada: a policy Delphi study. Personal genomes: Accessing, sharing and interpretation. Wellcome Genome Campus. Hinxton, UK, April 11-13th, 2019.
7. 2019 **Rahimzadeh V***. The present and future of data sharing in the postgenomic era. Quality Matters in Qatar—A Global Discussion. International Biobanking Conference, Doha Qatar, March 24-27th 2019.
8. 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, 2019. [**Invited FlashTalk**]
9. 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.
10. 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**]
11. 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.

12. 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**]
13. 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.
14. 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.
15. 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.
16. 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.
17. 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.
18. 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. 5th Plenary of the Global Alliance for Genomics and Health. Orlando, FL (USA) October 15, 2017.

19. 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. 5th Plenary of the Global Alliance for Genomics and Health in Orlando, FL (USA). October 15, 2017.
20. 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.
21. 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.
22. 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]
23. 2017 **Rahimzadeh, V***. Tool building for research ethics mutual recognition. ISBER Annual Meeting in Toronto, ON (CA). May 9-12, 2017.
24. 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.
25. 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.
26. 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.

27. 2016 **Rahimzadeh V[†]**, C. Schickhardt, J. Friedman, M.C. Cornel, S. Pfister, D. Avar, 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.
28. 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. 44th Annual North American Primary Care Research Group Meeting in Colorado Springs, CO (USA), November 13-17, 2016.
29. 2016 **Rahimzadeh, V[†]**; C. Schickhardt, J. Friedman, M.C. Cornel, S. Pfister, D. Avar, 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.
30. 2016 **Rahimzadeh V***, Martin Bobrow, Anna Petaja Leinonen. Ageing and Dementia Task Team Annual Report". 4th Plenary Meeting of the Global Alliance for Genomics and Health in Vancouver, BC (CA), October 16, 2016.
31. 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. 4th Plenary of the Global Alliance for Genomics and Health in Vancouver, BC (CA), October 17, 2016.
32. 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.
33. 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.

34. 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.
35. 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.
36. 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].
37. 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.
38. 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.
39. 2015 **Rahimzadeh, V***. Promoting an Ethic of Engagement. 11th Annual Pediatric Bioethics Conference. Seattle, WA (USA). July 24-25, 2015. [Student abstract scholarship winner].
40. 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.
41. 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.
42. 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.

43. 2015 **Rahimzadeh V***, Sénécal K, Avard D, Knoppers BM. Disclosing Incidental Findings in Pediatrics: Perceptions and Insights for Health Professionals. UNESCO Bioethics Chair 10th World Conference. Jerusalem, Israel. January 6 - 8, 2015.
44. 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.
45. 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.
46. 2014 **Rahimzadeh V***. Return of Incidental Findings in Pediatric Oncology. European Society of Human Genetics Annual Conference. Milan, Italy. May 30, 2014.
47. 2014 **Rahimzadeh, V***. To Disclose, or Not to Disclose? The Context Matters. Canadian Bioethics Society Annual Conference. Vancouver, British Columbia (CA). May 29, 2014.
48. 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.
49. 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.
50. 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.
51. 2014 **Rahimzadeh V***. Adolescents and Cancer Diagnosis. Fourth Biennial Bilingual Canadian Society for the

Sociology of Health Conference. Montreal, Quebec (CA).
May 6, 2014.

52. 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.
53. 2013 **Rahimzadeh V***. Engagement Ethics in Pediatric Palliative Care. Pediatric Palliative Care Research Group. Montreal Children's Hospital, McGill University Health Centre. Montreal, QC.
54. 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. Media Coverage

- 2018 **Canadian Institutes of Health Research (CIHR)**
Faces of Health Research: Project Pedigree
<http://www.cihr-irsc.gc.ca/e/50395.html>

6. Referees

1. Professor Mildred Cho, PhD **Associate Director, Stanford Center for Biomedical Ethics**
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