

**Spaces of convergence in a cancer clinical genomics  
trial: a survey examining genomic literacy among  
medical oncologists in British Columbia**

by

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## Approval

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## Ethics Statement



The author, whose name appears on the title page of this work, has obtained, for the research described in this work, either:

- a. human research ethics approval from the Simon Fraser University Office of Research Ethics

or

- b. advance approval of the animal care protocol from the University Animal Care Committee of Simon Fraser University

or has conducted the research

- c. as a co-investigator, collaborator, or research assistant in a research project approved in advance.

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## **Abstract**

The emergence of big data in the network age has led to many innovative breakthroughs in all sectors of life. One significant breakthrough are the prominent applications of clinical genomics in developing personalized medicine. In this thesis I explore the technological diffusion of clinical genomics within the spaces of convergence of multidisciplinary medical stakeholders in the Personalized Onco-Genomics (POG) cancer clinical trial. I co-developed the concept of “Genomic literacy” by drawing upon three areas of scholarship: health communication, information communication technologies (ICTs), and science and technology. I gathered data using a survey and semi-structured interviews with medical oncologists and other scientists at POG. Using this data I examine how genomic literacy, attitudes, and experiences of the domain experts working with clinical genomics can determine the adoption of genomic technologies into clinical care. These spaces of convergence of multidisciplinary medical stakeholders also create a pedagogical space where the stakeholders come together. This bioclinical collective of stakeholders learn more about genomics through their communicative and discursive processes, as they co-construct knowledge and meaning with genomic information.

**Keywords:** genomic literacy, spaces of convergence, social construction of technology, knowledge translation, diffusion of innovation, information communication technology, bioclinical collectives, biological citizens

*To my parents, my little sister, and my late grandfather,  
who lost his life while serving as a military nurse in the  
Vietnam War, before my father and I could meet him*

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## List of Acronyms

ANOVA	Analysis of Variance
BC	British Columbia
BCCA	British Columbia Cancer Agency
BRCA	Breast Cancer
CME	Continuing Medical Education
CPD	Continuing Professional Development
DNA	Deoxyribonucleic Acid
DTC	Direct-To-Consumer
EHR	Electronic Health Record
GDP	Gross Domestic Product
GIC	GeneInsight Clinic
GP	General Practitioner
HGP	Human Genome Project
HGSA	Human Genetics Society of Australasia
HNPCC	Hereditary Nonpolyposis Colorectal Cancer
ICTs	Information Communication Technologies
MOs	Medical Oncologists
PCPs	Primary Care Physicians
POG	Personalized Onco-Genomics
RNA	Ribonucleic Acid
SACGHS	Secretary's Advisory Committee on Genetics, Health, and Society
SCOT	Social Construction of Technology
SD	Standard Deviation
SFU	Simon Fraser University
UBC	University of British Columbia
UME	Undergraduate Medical Education
VUS	Variants of Uncertain Significance
WG/ES	Whole Genome or Exome Sequencing
WHO	World Health Organization

## Chapter 1.

### Introduction

Communications sciences and modern biologies are constructed by a common move-*the translation of the world into a problem of coding*, a search for a common language in which all resistance to instrumental control disappears and all heterogeneity can be submitted to disassembly, reassembly, investment, and exchange.

Haraway, 1985, 130

In March, 2015, Trish Keating appeared on many local news outlets thanks to treatment she received at the British Columbia Cancer Agency (BCCA) involving whole genome sequencing (Mulholland, 2015). Keating was diagnosed with stage 4 colorectal cancer, but none of the standard of care treatments including surgeries, chemotherapy, or radiotherapy, were effective to stop the spread of her cancer. After consulting with her oncologist, Keating enrolled in a cancer clinical genomics trial program called the Personalized Onco-Genomics (POG) in the hope of finding potential treatments for her incurable cancer. Through POG, her tumour and healthy DNA were sequenced and compared with other research participants in the database in order for her oncologist to identify effective drugs for targeting her cancer. Experts trained in both computer science and biology (called bioinformaticians) at POG took data yielded from one of the tumours in her spine and analyzed it to identify potential drugs that may target her specific cancer.

The goal of tumour sequencing is to tailor the treatment toward one's cancer based on the patient's genomic structure. The results identified a specific protein as the cause of her cancer. Hence, her oncologist put her on a low cost blood pressure medication to block that protein. Within five weeks, her stage 4 colorectal cancer went into remission, and Trish Keating has been living a healthy life since then. The local media news called Keating's case a "miracle" clinical trial (Keller, 2015). As of the time of this writing, Trish Keating has been living a happy and healthy life since her treatment at POG.

The miraculous case of Trish Keating is an accomplishment of sequencing technologies that opens up a new realm of data-driven personalized medicine for personalized treatment of cancer in the setting of experimental clinical trials. Cancer clinical trials are revolutionizing oncology practices into "more flexible, networked research arrangements, and towards using individual patients as model systems for asking biological questions" (Nelson et al., 2014, p. 74). The genomic structure of each individual is different and genetic alterations vary from tumor to tumor. As a result, in light of the advancement of biomedical innovations, medical practitioners diagnose, analyze, and treat diseases and illnesses on the basis of individual patient's genome compositions. However, despite massive funding and research by both public and private agencies for several decades, clinical application of genomic technologies is still facing many risks and hurdles in transitioning into primary clinical care (Khoury et al., 2007). In spite of the successful cancer treatment of Trish Keating, the local news covered a negative aspect of genomic medicine by reporting a conversation with Dr. Howard Lim, who is Keating's oncologist, expressing his skepticism towards genomics medicine as "[clinical genomics] is not an exact science and that's why it's still highly experimental"



(Mulholland, 2015). News media coverage of clinical genomics reflect both utopian and dystopian technological views, being both a “miracle” and “highly experimental”.

However, these characterizations of the advancement of medical biotechnology neglect the larger social transformations of our body, genes, and identity mediated by digital culture and information technologies.

### **Promises of genomics in reforming current health care systems**

Since the success of the Human Genome Project (HGP), advances in genomic technologies have incited many promises and breakthroughs in health care systems. In January 2015, President Obama announced the new “Precision Medicine Initiative,” with a budget of \$215 million for sequencing the DNA of one million volunteers in order to advance personalized medicine and genomics into clinical care (Herper, 2015). Across the Atlantic, the United Kingdom is also carrying out a four-year project of sequencing “100,000 Human Genomes” in the hope of finding the cure for cancer and other rare diseases (Gallagher, 2014). Genomic data helps scientists understand the molecular causes of diseases (Martin-Sanchez & Verspoor, 2014). Personalized medicine is a convergence between clinical medicine and computer engineering. By computing algorithms, medical practitioners can use medical big data of patients to predict drug responses and render effective therapies to patients. Clinical genomics opens up many pathways to human insights into causes and outcomes of diseases, disease prediction and prevention, and better drug targets for personalized medicine (Khoury & Ioannidis, 2014).

The rise of personalized medicine produces a paradigm shift in medical sciences by disrupting the traditional approach to health care, also known as population health. Population health is a paradigm of standardized care that follows a population-level average approach. For the past 60 years, traditional healthcare diagnostics treat patients as an average. This approach is problematic. In fact, according to a new report by the right-leaning Fraser Institute, the average Canadian family contributed \$11,735 in taxes for public health insurance in 2015 (Palacios & Barua & Ren, 2015). US government expenditure in healthcare is even higher. In 2012, National Healthcare Expenditure of the US reached \$2.7 trillion, which accounts for almost 17.5% of their GDP (Pianin, 2015). However, Canada and US ranked 30<sup>th</sup> and 37<sup>th</sup> respectively in the quality ratings for the world's health systems. These two superpowers ranked behind countries like Oman, Greece, Iceland, Israel, Cyprus, Chile and Costa Rica. The math doesn't seem right here. The more we spend on healthcare, the less we get back. So what are the problems?

The underlying defect of population health is that every one of us is different on the DNA level, and hence, medicine simply cannot treat all patients as an average. The genomic structure of each individual is different and genetic alterations vary from tumor to tumor. As a result, generic drugs or treatment protocols are not clinically effective for all individual patients. However, with the data-driven health care approach, medical practitioners diagnose, analyze, and tailor treatments of diseases and illnesses on the basis of individual patients' genome compositions. This approach in turn greatly optimizes patient care and decreases the cost of generic therapies used in the traditional population health. The cost of whole genome sequencing has dropped to thousands of dollars, and soon it will be a few hundred dollars. In 2003, the Human Genome Project, funded by the

government, cost \$2.7 billion to sequence a human genome, consisting of all three billion chemical units in the human genetic instruction set (Lohr, 2013). By late 2015, the cost to generate whole genome sequencing has fallen to \$1500 (NIH, 2016). It is predicted that in the next three years, that \$1500 testing cost will go down to only \$100.

In private genomic testing industry, 23andMe, a Californian-based DNA testing service, offers a \$250 package for DNA testing to find out our personal genetic information (Murphy, 2013). In biotechnology industry, genetic testing market is rapidly expanding with the boom of biotechnology stocks in the past two years (Herper, 2014). The biotech boom has been fueled mostly by innovations in therapeutics, the creation of new lucrative drugs and the research breakthroughs in life sciences. With the decreasing cost of genetic testing and the development of biotechnologies, the public now also has easier access to the structure of their genes and detecting the risk their genetic diseases. Medical practitioners are increasingly dealing with this new information in their practices. However, their level of genomic knowledge is often inadequate in order to make treatment decisions based on a patient's genome sequencing information (Gray et al., 2014). Doctors and other front-line health professionals need access to better genomics knowledge in order to incorporate this new information and technology into patient care. Yet, there is a dearth of genomic education in their medical education and training. The thesis defines this type of education "genomic literacy."

Understanding a genome sequence is a highly specialized skill, requiring at least a post-graduate Ph.D. degree in molecular biology. Traditional medical education does not sufficiently train doctors to read and understand human genome data. Therefore, in clinical genomics, doctors collaborate with other medical experts such as

bioinformaticians or genome scientists to interpret and apply genomic information into clinical practice. This engenders a paradigm shift in medical practices and medical knowledge. It also paradoxically creates uncertainties in diagnostic along with hopes of potential treatments. This paradox impacts the nature of diseases, life strategies, as well as identity and subjectification of patients. As a result, the paradigm shift in medical practices and medical knowledge is the key focus of genomic literacy, aiming to explore the biomedical and social disruptions of genomic science in clinical care.

## **Clinical gaze versus molecular gaze**

The birth of the clinical gaze at the early 19th century inaugurated by Michel Foucault presents one of the most fundamental philosophies to understand social relations between power, knowledge, and the body. Early 19th century was the golden age for clinical medicine in which medical diagnosis extended beyond the two-dimensional space of tissues and symptoms to the pathological anatomy and post-mortem dissection of cadavers in hospital (Rose, 2007). As a result, the clinical gaze gave rise to a new medical territory in which doctors had the therapeutic powers and control over human bodies and diseases (Armstrong, 1983, 1995; Arney & Bergen, 1984; Starr, 1982). Under the clinical gaze, doctors gained power and control to manage chronic illness and death, administer reproduction, govern health risk, and promote guidance on how to conduct a healthy lifestyle. This medical regime allowed doctors to not only manage human health and diseases, but also interfere with children's sexuality, women's reproduction, biological kinship, sexual discourse, pleasures, and human psychiatry (Foucault, 1978).

In such a milieu, the medical imperialism gave doctors and practitioners the power over our social, moral, and political realms.

As we entered 20th and 21th century, clinical medicine was transforming into technomedicine, contingent on complex diagnostic tests and therapeutic technologies (Clarke et al., 2003; Horton, 2004). The technomedicine engenders a complex multidisciplinary collaboration among medical experts and specialists in rendering diagnostic and clinical decisions for patients. As a result, doctors no longer hold the primary clinical knowledge and power over human health and vitality. Clinical decisions, in the age of technomedicine, are also no longer based on solely clinical knowledge and judgments of doctors, but defined by evidence based medicine, standardized diagnostic, and treatment protocols. With the advancement of DNA and genomic sciences, doctors and scientists are now able to perform medical diagnosis based on molecular structures of our body. Under this molecular gaze, modern biology deconstructs human biological properties into informational data and computer codes. The discovery of the structure of DNA made it possible to represent the basic matter of life with permutations and combinations of just four letters of the English alphabet: A (Adenine), C (Cytosine), G (Guanine), T (Thymine) (Watson & Crick, 1953; Jasanoff, 2011). These four simple letters carry a sociotechnical power that constitute “the book of life” and engender the field of biotechnologies, enabling a discourse of information and rule to shape biological, social, and cultural formations of individuals (Kay, 2000; Fox Keller, 2000). In this molecular gaze, biotechnology has created new forms of life, including stem cells and embryos, altering fundamental notions of human existence and identity (Epstein, 2007;

Haraway, 1997; Rabinow, 1992), and disrupting the traditional forms of biomedical knowledge and practices (Cambrosio & Keating, 2011).

The complex intersection of health, medicine, and technology in the increasingly mediated world of biomedicine lies at the heart of this thesis. In order to understand the diffusion of genomic technology into clinical care, we need to examine not only genomic literacy among physicians who are the domain users of the technology, but also the disruption genomics brings about in medical education systems and practices. Through the domains of health communication, information communication technologies (ICTs), and cultural theory of technology, this thesis explores the critical discrepancies between promises of clinical genomics and the social implications of genomics in medical education and practices. I will examine genomic big data as spaces of convergence between multidisciplinary stakeholders from emerging fields of molecular biology, computer engineering, and medical science, whose epistemic cultures and social agendas shape the meaning-making of genomic information through communication and discursive processes.

## **Research objectives and Rationale**

This thesis examines the social shaping of genomic technologies mediated by a new technological paradigm in biomedicine converging medical sciences with information technologies and computing analytics. I will build my analytic frameworks from scholarly work on spaces of convergence (Chow-White & Garcia-Sancho, 2012) and bioclinical collectives in clinical genomics (Cambrosio & Keating, 2011). Using

these frameworks, I am specifically interested in exploring how clinical genomics constitutes spaces of convergence or a “new style of practice”, generating novel and distinctive ways of producing medical knowledge for cancer treatments via large-scale biocollectives of medical stakeholders, patients, treatment protocols, drugs, and biotechnology. Clinical cancer genomic trials are spaces of convergence between a network of clinical stakeholders, manifesting the translational multidisciplinary in narrating meaning and diagnosis of genomics information. I will develop the concepts of genomics as a form of medical big data and clinical trials as a network of multidisciplinary collaboration. Medical practitioners have their own style of reasoning and practice, or epistemic culture, toward how medical knowledge is produced (Cetina, 2009). As being a part of the biocollectives, their epistemic cultures are situated within a social positionality or shifting networks of relationships with other practitioners in the platforms of translational research (Keating & Cambrosio & Nelson, 2016). As a result, clinical cancer genomic trials like POG manifest the social construction of genomic technologies, as it represents spaces of convergence where the communication and discourse processes between different stakeholders shape the technologies and meaning-making of the information. Genomic literacy plays an important role in understanding the individual style of reasoning and social relations between different medical practitioners emerged from the meaning-making communication process of genomic information.

Based on survey, interviews, and a brief participant observation with medical specialists, I will argue that clinical genomics clinical trials illuminate communication culture of medicine where the meaning making of genomic results takes place through the interactions, discussions, and communication of the multidisciplinary medical

stakeholders. Multidisciplinary clinical genomics trial programs also carry a sense of sociotechnical imaginaries, representing aspirational and normative dimensions of biological social order. My central research question is: How does communication and discourse processes between different medical specialists influence meaning making of genomic information in clinical cancer trials? Through the lens of their genomic literacy and communication processes, I will study public understandings of genomics and the actualization of clinical genomics. The intent of this research is to provide an insightful analysis of critical theories that are concerned with social transformations of our body, genes, and identity mediated by digital culture and information technologies.

## **Overview of Thesis**

It has been over a decade since the completion of the Human Genome Project in 2003 that gave rise to the biomedical innovations in genomic science and technology. However, until today, genomic technologies are still facing many hurdles and challenges in the transition into clinical care. This thesis explores the technological diffusion of genomics into oncology practice, while accounting for the co-production of science, technology, and society in the setting of cancer clinical trials. The second chapter of this thesis “Spaces of Convergence of Genomics” introduces insightful analysis of critical theories built upon the concept of literacies to study the diffusion, adoption, and social implications of genomics medical big data in clinical cancer trials. In order to examine the diffusion of genomics, I co-construct with my senior supervisor Dr. Peter Chow-White the concept of *genomic literacy*, drawing upon three areas of scholarship: health



communication, information communication technologies (ICTs), and science and technology. Genomic literacy focuses on the spaces of convergence in the knowledge production of genomic information between multidisciplinary medical stakeholders in cancer clinical trials. By understanding the genomic literacy of stakeholders, this chapter highlights the social shapings and implications of genomic information in the multidisciplinary experimental clinical trial. Central mechanisms of genomic technologies are emerging fields of computers, the Internet, and digital databases. To this end, I argue that genomics is the product of social structures and activities processed and mediated by micro-electronic based technologies, known as the network society. In other words, genomic information is not merely a type of medical knowledge, but a form of big data enabled by computer metaphors of information and communication technologies (ICTs). Then I explain how cancer clinical trials illuminate these spaces of convergence between multidisciplinary medical stakeholders with different sets of knowledge, skills, and styles of reasoning. These spaces of convergence render a new style of practice in oncology and challenge the traditional approach to cancer research and healthcare, constructing fluid and hybrid networks of the clinical, biological, and informational realms. The chapter ends by discussing the paradigm shift, produced by genomic technologies, in understanding methods and cancer treatments that leads to a new upheaval of social relations in oncology practices, and how these social relations influence the narratives of risks and uncertainties in genomic data.

Chapter Three describes my methodologies including a survey and semi-structured interviews to examine the adoption of genomics into clinical care. The empirical research of this thesis is a collaborative project with BCCA to examine the

values of POG. Therefore, this research is a co-production between scientists and medical specialists at POG and social researchers at SFU. For this project, we co-constructed a survey based on semi-structured interviews, consultations, and validity check with medical specialists at POG. This survey functions as a user exit survey aiming for oncologists, who are the domain users of the genomic technologies and data. The main goal of this survey is to identify the potential values and challenges of applying genomic technologies into clinical practice in the context of cancer clinical trial at POG. The project aims to produce fruitful results to understand and better advance the technological diffusion of genomics into clinical care. This methodology chapter outlines the process and rationale of designing our survey instruments including semi-structured interviews with project principles at POG, literature review on other similar survey protocols, survey design, pilot survey, data collection, and data analysis.

Chapter Four “Genomic Literacy” returns to the first element outlined in the introduction, the genomic literacy. This chapter reports findings from the survey, focusing on the level of genomic knowledge and education about clinical genomics among physicians. By examining the level of genomic literacy among physicians, we can understand the challenges in knowledge translation of genomics into clinical care. The findings in this chapter support our central argument that genomic technologies engender a new style of practice in oncology and challenge the traditional approach to medical education and practice. An interesting finding in this chapter shows that POG has an important pedagogical role of teaching and training physicians about genomics through the multidisciplinary collaboration between different medical stakeholders. By

representing spaces of convergence, or the meetings of the minds, POG instills and maintains the hopes of both the oncologists and the patients for personalized effective cancer treatments. As such, the co-production in experimental clinical trials like POG articulates genomics with a sense of hope and promises for personalized cancer diagnosis and treatment, as well as sociotechnical imaginaries constituted by the social orders of science, technology, and society.

In Chapter Five “Co-production of Genomics”, I examine the role of communication and discourse in the knowledge production of genomic information. This chapter highlights the critical discrepancies between the promises of clinical genomics and the social implications of diagnostic results. While many stakeholders are optimistic about the applications of genomics into oncology practice, many others are still skeptical and reluctant to adopt this diffusion. Rapid expansion of genomics and biomedical innovation can generate novel knowledge and diagnostic uncertainty about genomics. Biomedical uncertainty has significant impacts on the life decisions of patients, the nature of disease, and the identity of patients. This chapter discusses the implications of a classification system of biomarkers that medical stakeholders at POG are developing to overcome this diagnostic uncertainty of genomics. I argue that the meaning-making of genomic data in developing a classification system postulates a complex decision-making process through communication and discourse between multidisciplinary medical stakeholders. The classification systems encodes an inextricable network of human actions, politics, arguments, agreements, agendas, values, and social relations of different actors, manifesting the spaces of convergence between different styles of reasoning and practice, or epistemic cultures, in the knowledge production of genomic data.

Genomics is on the horizon of future health care and oncology practice. However, there is still an immense bridge between knowledge and application among physicians for genomics to be fully adopted in clinical settings. Until then, genomics will still be remaining our hope technologies, postulating an imagined but achievable future that will defeat the patient's illness and suffering and advance clinical innovation of genomic technologies. In Conclusion chapter, I discuss implications of this research on communication study of the spaces of convergence, practitioners, and clinical genomics. I also propose potential ideas for future directions of this field of research. I sum up the thesis by recapitulating the overarching narratives of genomic literacy in the spaces of convergence that influence the adoption of genomic technologies and the knowledge co-production of genomic information. Finally, this thesis ends with outlining future endeavors ahead for genomics and imagining a utopia world in which everyone will be getting her or his own genome sequenced in utero, before birth. In that new ontology of life, our self, identity, body, and mind will be in the forms of numerical and informational codes of a "dividual" or technological plasticity mediated and manipulated by digital culture and information technologies.

## Chapter 2.

# Spaces of convergence of genomics in the network age of big data

The technological revolution, with its two major and interrelated fields, in micro-electronics-based communication technologies and genetic engineering, has continued to accelerate, transforming the material basis of our lives.

Castells, 2010, xliv

Clinicians and decision makers have been developing and adopting genomic technologies with scientists for medical practice with the hopes of improving medical outcomes. For example, in multidisciplinary clinical genomics trials, oncologists collaborate with a scientific research team to analyze and evaluate meanings of genomic data for potential cancer treatments, and thus bridge clinical and research settings together (Keating & Cambrosio, 2011; Nelson et al., 2014). In the genomic era, physicians need to be able to understand, interpret, and apply genomic data into treatment plans with at least a basic level of confidence and competency for the application of genomic technology in the health care system. However, one of the major challenges in this process is knowledge translation of genomic services into clinical care. The rapid expansion in genomic science and biomedical innovations produces knowledge and information that can generate uncertainty in the clinic and cast doubt among clinicians on how to interpret and apply genomic data into clinical practices (Berg, Khoury, & Evans, 2011; Bombard, 2015). Clinicians struggle with interpreting and applying genomic data into clinical practices, which has tremendous impacts on ontologies and practices surrounding disease, the identity of patients, and life strategies of patients like treatment

decisions (Timmermans & Buchbinder, 2010). A useful step in meeting this challenge is to understand the current level of genomics knowledge amongst physicians.

In this thesis, I aim to explore the knowledge and attitudes of oncologists toward genomic sciences and technologies through the concept of “*genomic literacy*”. “Genomic literacy” studies the social construction of genomic information through the co-production of science, biotechnology, and society in the network age of big data (Jasanoff, 2004). I examine the three trajectories of health communication, network society, and science and technology to analyze the social implications of genomic literacy. The emergence of genomic sequencing in oncology marks a significant outcome of the convergence between big data and public health. Yet, genomic technologies are still immature and full of uncertainties, which in turn are yet to be considered an actual science that can be applied in clinical practices. Drawing upon scholarly work of diffusion of innovation in the context of health care (Rogers, 2010; Christensen, 1998, 2006; Oldenburg & Glanz, 2008), I argue that genomic technologies are in the process of diffusing into clinical care as they challenge the traditional medical school education systems, and engender different knowledge models and new styles of medical practice. In this milieu, it is worthwhile to explore the social shaping of genomic technologies as it is being diffused into our healthcare systems, in order to understand the heterogeneity and multidisciplinary at the heart of the technologies. Many scholars have argued that to critically understand the development of public health praxis, we need to go beyond the dominant biomedical and behavioral approaches in health communication, and put more emphasis on the ideology, power, and discourse embedded within health apparatuses (Salmon, 1989; Wallack, 1989; Lupton, 1994; Tulloch & Lupton, 1997; Airhihenbuwa,

1995, 2007; Guttman, 2000; Dutta, 2006, 2007; Dutta-Bergman, 2004, 2005; Khan, 2006). The study of rhetoric and discourse is crucial in understanding what scientists and other gatekeepers believe and how they believe it, which in turn shapes the production of scientific and technical knowledge (Foucault, 1978; Latour & Woolgar, 1979[1986], Sismondo, 2004). As an example, scientists express or represent genes and DNA by the dominant metaphors of informational terms and codes (Kay, 1995). Therefore, language and discourse are the means for scientific knowledge to converge itself on a mirroring relation to nature in which it becomes representations to things in the world (Lynch & Woolgar, 1990; Pickering, 1995). Drawing upon Castells' scholarly work of information age and network society (2010), modern biology and genomic sciences have transformed our biological properties into informational representation of data and codes, also known as medical big data.

With the rapid advancement of biotechnology, genomic information has become as a form of medical big data, generating a new technological paradigm for medical practices and a network of multidisciplinary collaboration in cancer clinical trials. I argue that multidisciplinary clinical trials illuminate a new style of practice, consisting of spaces of convergence between different clinical stakeholders and social groups with distinctive skills and expertise, problems, and solutions engaging in an extricable network to co-produce knowledge of genomic technologies. Using the encoding and decoding model (Hall, 1993), I argue that there is an asymmetry or lack of equivalence in knowledge and skills between different social groups in the clinical trials network, leading to an asymmetry or an uncertainty to translate or make meaning of genomic data. Hence, in a multidisciplinary clinical trial, there is a need to build a '*translatability*'

between experts involved (Latour, 2005, 2013; Pinch & Bijker, 1987); in POG, this includes medical oncologists, bioinformaticians, medical geneticists, pathologists, and scientists. In other words, genomic technologies need to have an '*interpretive flexibility*' facilitated by communication, rhetoric, and discourse in the cooperation and collaboration between multidisciplinary social groups (Foucault, 1978; Latour & Woolgar, 1979, Sismondo, 2004). Therefore, genomic technologies as *boundary objects* that traverse across different stakeholders by collaboration and communication among heterogeneous practices on equal terms, shaped by their skills and expertise, in turn leading to the meaning making of the information (Star & Griesemer, 1989; Duncker, 2001).

Drawing upon science studies and cultural theory of technology, I will explore spaces of convergence between a network of clinical stakeholders in a cancer clinical trial, manifesting the translational multidisciplinary in negotiating the uncertainty of genomics information as well as the adoption of genomic technologies in clinical care. The production, understanding, and application of clinical genomics big data are a cultural and discursive product formed by multidisciplinary communication and collaboration between different medical stakeholders. I will also draw upon a descriptive analysis from our participant observation, interview, and survey data to illuminate that clinical genomics clinical trials challenge the traditional approach of population health and disrupt the existing frameworks of medical knowledge (Ha et al., 2016, under review). This disruption leads to many uncertainties for the diffusion of genomic technologies into primary care systems. On the other hand, this disruption brings about a sense of hope for clinicians and patients regarding effective treatments for their diseases. Therefore, I also argue that experimental clinical trial programs carry a sense of



sociotechnical imaginaries, representing aspirational and normative dimensions of biological social order (Jasanoff, 2015). As such, the advancement genomic technology renders a new ontology of life: our DNA and vitality are decomposable, storable, bankable, and commodifiable (Waldby & Mitchell, 2006; Hayles, 2008; Landecker, 2009; Rose, 2009; Myers, 2015). The intent of this line of research is to provide an insightful analysis of critical theories built upon the concept of literacies to study the diffusion, adoption, and social implications of genomics medical big data in clinical cancer trials.

## **Genomic literacy from health communication perspectives**

In order to examine the biomedical and cultural values of genomics medical big data, I co-developed with my supervisor a definition for genomic literacy based on the concepts of health literacies (Hurle et al., 2013; Jensen, 2011), media literacy (Potter, 2011), and encoding/decoding model (Hall, 1993). The National Human Genome Research Institute at the National Institutes of Health defines genomic literacy is the understanding of what a genome is, how genomic science works, its affordances and limitations, applications, and impacts on society (Hurle et al., 2013). On a deeper level, genomic literacy carry two different facets including genomic science literacy and genomic health literacy. I focus on genomic literacy in the context of health care. I draw on health literacy as "the capacity to obtain, process and understand basic health information and services needed to make appropriate health decisions" (Jensen, 2011, p. 172). Genomic literacy in health focuses on the ability to generate, analyze, interpret,

understand and apply genomic data in the context of health-related decision-making or clinical practices. These concepts, however, only approach health literacy from a technical and biological level. I want to explore genomic literacy from a deeper and more philosophical dimension to understand the social, cultural, political and economic implications of genomic sciences and technologies. In order to do so, I am going to borrow the concepts of literacy from media and cultural studies.

In media and cultural studies, media messages are always encoded with dominant ideologies and hegemonies to produce consensus or manufacture consent in modern societies (Hall, 1982). Therefore, Potter (2011) coined the term “*media literacy*” as a repertoire of competencies to turn passive consumers of media content into active and critical agents. Potter defined “media literacy” in a multidimensional continuum as “a set of perspectives that we actively use to expose ourselves to the media and interpret the meaning of the messages we encounter” (p. 14). Media literacy also consists of skills used to work on media information to produce knowledge structures of media messages. Traditionally, mass communication research conceptualized the process of media consumption and human communication in a linear *transmission model* developed by Shannon and Weaver (1949). However, the model faces many criticisms, most notably the ones from Stuart Hall. Hall heavily criticized the linearity of the sender/message/receiver transmission model due to its simplicity, and its lack of a complex structure for the power, ideologies, and social relations embedded within the communication process. Instead, Hall proposed a circulation circuit or loop of four linked but distinctive stages in his encoding/decoding model: production, circulation, distribution/consumption, and reproduction. At the encoding (production) and decoding

(consumption) stages, each comprises three determining factors to encode and decode the message, which are frameworks of knowledge, relations of production, and technical infrastructure. Any lack of equivalence in any one of those three determining factors between the two stages can result in the asymmetry or the inability to translate or make meaning of the message. To overcome this lack of equivalence in the process of encoding/decoding, actors mediate their human relations and co-produce knowledge through communicative and discursive processes that are embedded with social practices, political agendas, epistemic cultures, and institutional ideologies (Jasanoff, 2004; Chow-White & Green, 2013). Therefore, the production of genomic information, like any form of knowledge, transforms the biological and molecular data and information of our genome into forms of discourse and language under sets of ideologies and social relations as signifying practices of communication processes.

In order to critically examine the social relations between knowledge and power encoded into genomic information, I drew upon Foucauldian terms of literacies as "controlled insertion of bodies into the machinery of production and the adjustment of the phenomenon of population to economic processes" (Foucault, 1980, p. 141). The concept of literacy can also be interpreted as more than just a set of skills or an orientation to the world, but it is also a critical examination and interpretation, and higher forms of thoughts about every social practice articulated in all aspects of life (Graff, 1979, 1987; Druick, 2016). As a result, another key focus of genomic literacy is social relations between medical stakeholders in the meaning making process of genomic information. Amalgamating all the aforementioned trajectories of health communication, media communication, and cultural approach to technology, Chow-White and I define genomic

literacies as an *action-oriented engagement and repertoires of multidisciplinary competencies that enable health professionals to analyze, collaborate, communicate, and apply genomic information, based on translational understanding of its affordances and constraints in science, medicine, and society* (Ha & Chow-White, 2016, under review). Taken together, genomic literacy is a form of knowledge and a way to understand how the knowledge is produced. Therefore, genomic literacy manifests biomedical and sociocultural implications that genomic sequencing technologies are bringing about. Using the concept of genomic literacy, we can assess the level of genomic knowledge among health professionals for clinical decision-making, and critically examine the sociotechnical changes of genomics as a new ontology of life where our tissues, cells, and genome can be decomposed, re-engineered, commoditized and transformed into medical big data and code as parts of a control network society.

## **New forms of medical knowledge: genomics as big data and code in the network age**

With the rise of the Internet and big data, our health and well-being are being mediated through digital codes and information. The World Health Organization (WHO) defines health as a “state of complete physical, mental and social well-being” (Costello, 1977, p. 558). WHO also realizes that health is not a stable entity but a dynamic process or a constant state of change (Wright et al., 2008). As society changes and technology advances, health has become a more complex matter. Health has been digitalized. The implications of digitized health care one of the main focuses in health communication study. From a health perspective, communication involves different aspects of human

communication, organizational communication and the role of new technologies in shaping health itself. In this thesis, I focus on the last perspective of health communication that is the impact of genomic technologies on human health. Genes are the units of heredity. It was first illuminated in the 1860s by Gregor Mendel, who tried to understand what causes the traits in pea plants, such as wrinkly pea skin, passing from one generation to another (Caulfield, 2012). It was not until 1953 that the structure of the unit of heredity for Deoxyribose Nucleic Acid (DNA) was published in a one-page article in the journal *Nature* by American biologist James Watson and English physicist Francis Crick. The discovery by Watson and Crick led to a variety of new technologies that allowed scientists to read the biological code of human DNA. This ability to analyze human DNA brought higher ambitions in bioscience to sequence the whole human genome. The sequence of human genome is the study of a 3-billion base pair consensus sequence of the euchromatic portion generated by the whole-genome shotgun sequencing method (Venter et al., 2001). The development of human genome sequencing has generated a profound transformation in biomedical innovation.

By decoding our human genome, we can understand the differences in DNA mutations that result in complex diseases (Chow-White, 2008). The two well-known projects that study the human genome are: The Human Genome Project (HGP) and the Human Haplotype Map (HapMap). In 1990, the HGP was launched in the United States with the funding of three billion dollars. It took nearly a decade and a whole team of experts around the world to finish it in 2003. In 2003, 99 percent of gene-containing part of human DNA sequence was sequenced with 99.99 percent accuracy (Caulfield, 2012). The significance of this project is immeasurable. As stated by the director of the National

Institutes of Health, the goal of the HGP is to improve human health and reduce the burden of disease for all people. The second project applies a different method to study our DNA. The HapMap project studies our genomes at different population groups of European descent, the Yoruba population of African origin, Han Chinese group from Beijing, and Japanese people from Tokyo (Bush and Moore, 2012). The purpose of the HapMap project is to understand the variation in genomic compositions across different ethnic groups for the advancement of personalized medicine and treatments for diseases in accordance to our race and personal genome.

Since the discovery of the DNA double helix structure by James D. Watson and Francis Crick in 1953, processes of reading human DNA and RNA molecules as codes and data have advanced moving from time-consuming manual processes to highly automated processes allowing the sequencing of whole genomes in a few days (Shendure & Ji, 2008). Canguilhem states that the underlying structure of modern molecular biology or of life itself transforms our biological and mechanical matters into information and communication technologies (Canguilhem, 1994; Rabinow, 1994; Franklin, 2000). The success of genomic technologies was the result of the emerging fields of computers, the Internet and digital databases (Chow-White, 2008). As a result, genomics is the product of social structures and activities processed and mediated by micro-electronic based technologies, known as the network society (Castells, 2010). In other words, genomic information is not merely a type of medical knowledge, but a form of big data enabled by computer metaphors of information and communication technology (ICTs) (Kay, 2000; Fox Keller, 2000; Hilgartner, 2015). As Haraway discusses in her book *Cyborg Manifesto* (1985), contemporary biotechnologies translate the world of biology and

human genome into a problem in coding and algorithm, blurring the dualisms between mind and body as well as culture and nature. In such a milieu, WGS transforms biological nature of our body, genes, and tissues into technological plasticity mediated and manipulated by digital culture and information technologies (Landecker, 2007).

Genomic sciences and research are made possible by emerging Internet technologies, or the network of different open data sources, digital databases and the collaborative work of scientists and experts around the world. As a result, the rise of personal genomics is one of many inevitable products of social structures and activities mediated by micro-electronic based technologies in the network society (Castells, 2010). The logic of network societies prioritizes the power of flow over the flow of power operating in a non-linear power relation through decentralized relations of sociability. However, network power is not democratic, but it is a form of power that the more users belong to or follow a node, the more dominant that node is, and the dominant nodes can edge out the rival ones (Hardt & Negri, 2001; Grewal, 2008). As the network grows and expands, it does not destroy or annex new nodes but includes them in the network so that nothing is outside of the network. Therefore, the network power reinforces a larger control society where individuals become “dividuals” or nodes, and masses become data, clusters, modules or banks (Deleuze, 1995; Levina, 2010). Our dividual identities also become objects constituted by information, connected, and managed as a part of network power within a topology of control. As a result, genomic sciences and technologies are the products of control societies operating within the network power that sequence and decompose our body and mind into fragmented and socially constructed dividual identities, or identities in-flux, to exist as nodes in the larger network of biological

control. In the following sections, I will examine the social transformations of clinical cancer genomic trials into spaces of convergence, manifesting a new style of practice and a bioclinical collective network in the knowledge production of genomics big data and biological social order.

## **Cancer clinical trials as spaces of convergence**

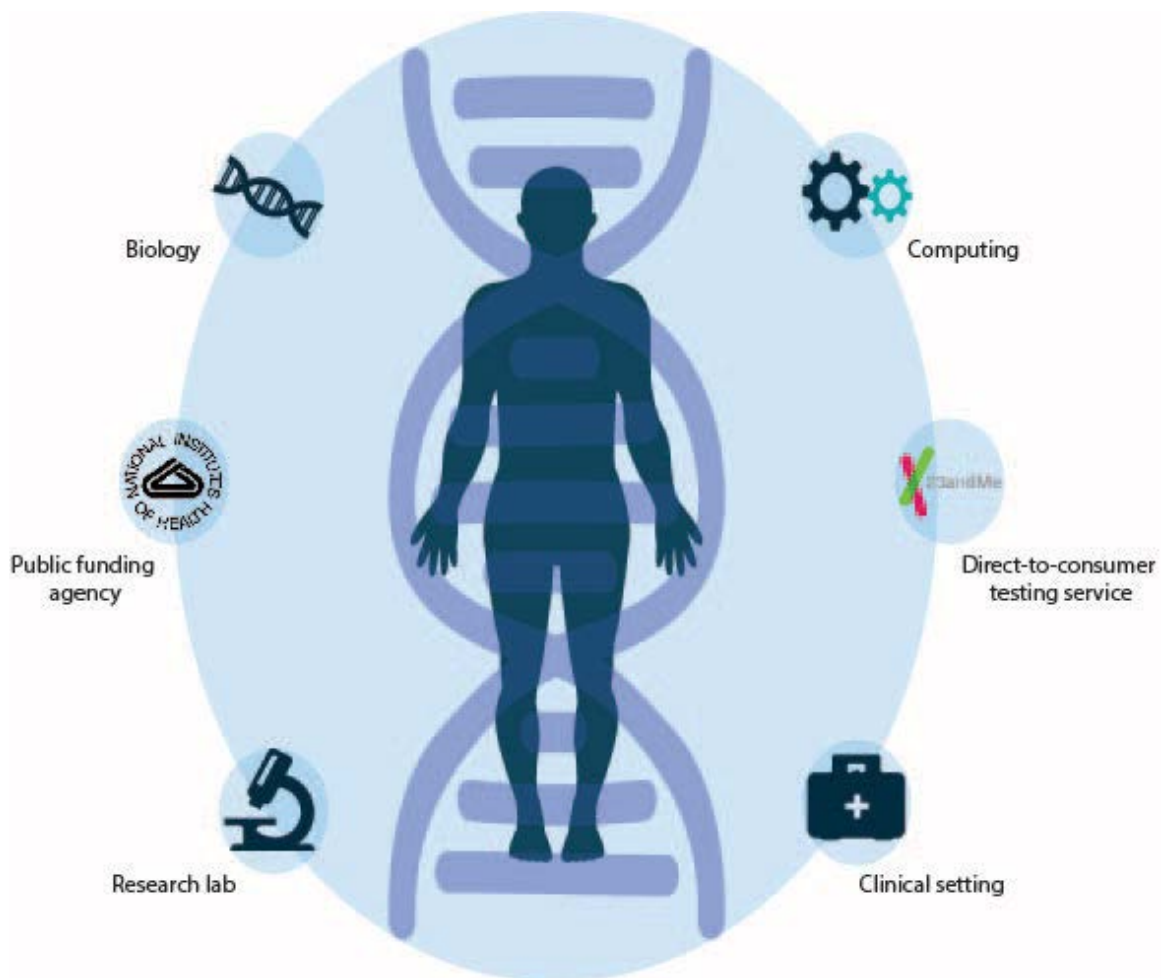
Cancer clinical genomics trial is an experimental system using genomic sequencing technologies to identify potential treatments and diagnosis for incurable cancer patients. The trial is a form of information communication technology as it generates medical big data from genomes, transcriptomes, and other types of biological and medical information. Cancer clinical genomics trial, entitled Personalized Onco-Genomics (POG), is the central research site for this research. POG is a clinical research initiative applying clinical genomics into the diagnostic and treatment planning for patients with incurable cancers. As of this writing, POG's enrolment is over 780 patients and includes 50 pediatric cancer cases. At POG, each patient undergoes a tumour biopsy and has comprehensive DNA and RNA sequencing. Tumour sequencing can produce massive amount of data that requires a lot of coding to analyze. Each patient case represents 1.5 terabytes of data that needs interpretation. This is big data. Genome scientists perform genomic big data analyses using computer algorithms and statistical analyses to identify variants that may be cancer "drivers" or therapeutically actionable targets. Then, oncologists use the results to identify any known drugs that can target the cancer drivers (Laskin et al., 2015). Therefore, tumor sequencing or genome sequencing



represents a bidirectional convergence of biology and computing (Chow-White & Garcia-Sancho, 2012). In other words, one of the main sectors of biology sciences has become “an informational science” that converges with computing science. As such, cancer clinical trials exemplify a new style of oncology practice and spaces of convergence between biology and computing sciences, and between multidisciplinary clinical researchers. Chow-White & Garcia-Sancho (2012) define spaces of convergence as “technologically mediated processes of communication. They are the space of flows of people, disciplinary expertise, finance, cultural values, institutional ethics, technology, information, data and code” (p. 130). The integration of computing and biology creates spaces of convergence between the forms, meanings, and functions of biology and computing, and blurs the lines between clinical experimental trials and medical practices. Taken together, I argue that cancer clinical trials represent spaces of convergence in big data clinical genomics comprising medical sciences and computer engineering, public funding agencies and private direct-to-consumer genetic testing services, and clinical settings and research labs (Figure 1). They arguably constitute a “new style of practice”, generating novel and distinctive ways of producing medical data for cancer treatments via large-scale interdisciplinary networks of medical stakeholders, treatment protocols, and drugs (Keating & Cambrosio, 2011; Nelson et al., 2014). As a new style of practice, genome sequencing findings, produced by cancer clinical trials like POG, not only challenge the traditional approach to cancer research and healthcare, but also construct fluid and hybrid networks of the clinical, biological, and informational realms (Nelson et al., 2013).

As the spaces of convergence in cancer clinical trials generate a new style of practice in medical oncology, they also produce new kinds of medical data and information, and create new criteria of truth and new forms of intersubjectivity. The concept of “style of practice” lies at the heart of Ian Hacking’s *style of reasoning* (1992a, 1992b). Hacking’s *style of reasoning* refers to a branch of sciences, such as observational sciences, experimental sciences, laboratory sciences, or computing sciences, having its own domain of objects, methods of collecting evidence, ways of explanations, and criteria for assessing results and producing facts. In the spaces of convergence, cancer clinical trials represent a myriad of styles of reasoning that combine different fields of sciences, manifesting a bioclinical collective of distinctive medical skills and knowledge of clinicians, computer specialists, and medical geneticists. This new style of practice gives rise to an emerging breed of experts called bioinformaticians. The spaces of convergence and new style of practice in cancer clinical trials resonate with Michel Foucault’s *dispositif* (1994), also known as *apparatus*. A *dispositif* refers to a “heterogeneous set of discourses, institutions, architectural arrangements, regulatory decisions, laws, administrative decisions, scientific statements, philosophical, moral, philanthropic propositions, in short, the said and the unsaid...the *dispositif* itself is the network that connects these elements” (Foucault, 1994, p.299; Keating & Cambrosio, 2011, p. 20). In another word, a *dispositif* comprises an assemblage of knowledge, power, subjectivity, buildings and spaces, discursive and non-discursive forces, intertwined as a network that articulates social orders and governmentality. In clinical cancer genomic trials, a *dispositif* produces a network of medical stakeholders and a bioclinical collective of relations and judgements in negotiating the clinical decision making of genomic

medicine. As a result, the cancer clinical genomics trial systems are a reflexive and collective network, identifying treatments and diagnosis on the basis of multidisciplinary styles of reasoning and practice. Genomic literacy plays an important role in understanding the individual style of reasoning and the tensions emerged from the collective styles of medical practice. In this next section, I will investigate the social and discursive relations of bioclinical collectives in the meaning making of genomic big data.



**Figure 1. Cancer clinical trials as spaces of convergence**

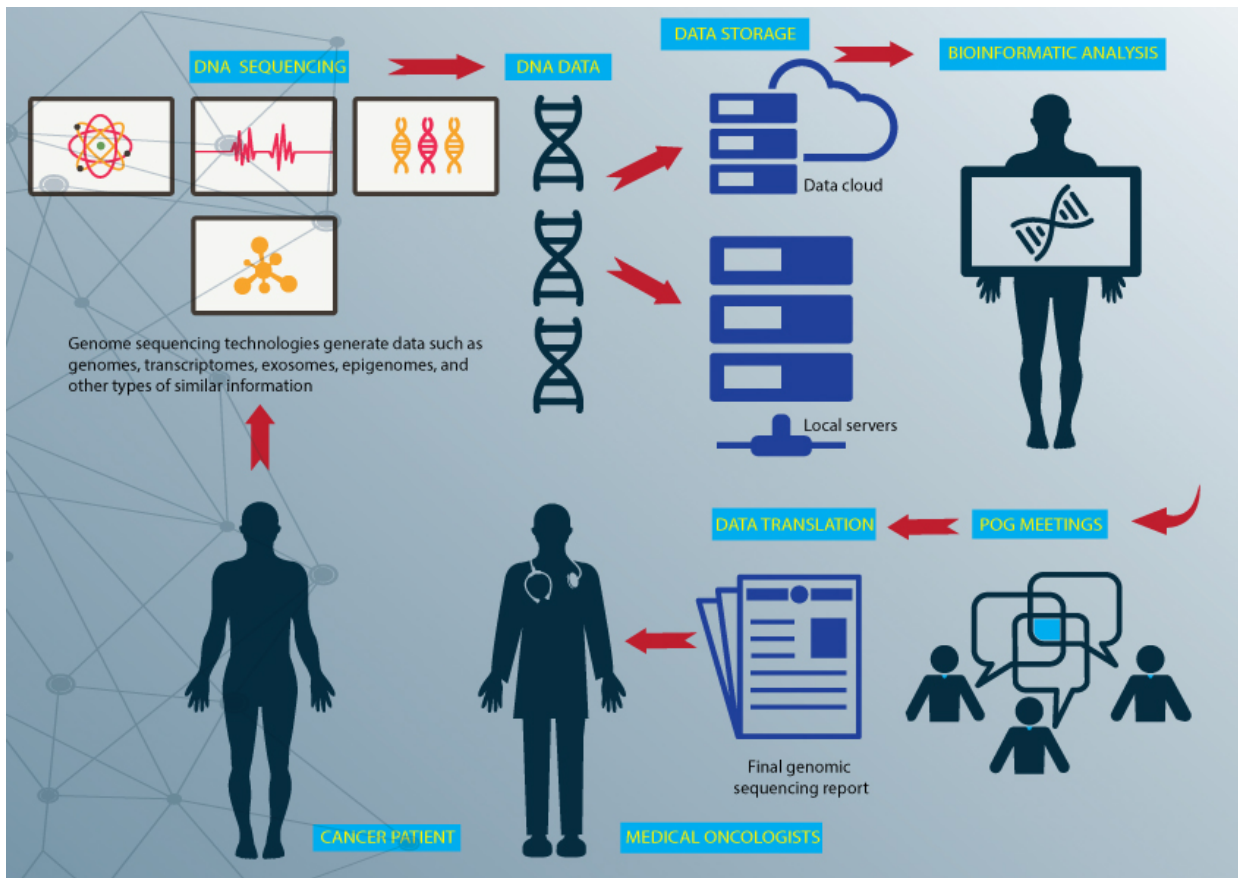
## **Social and discursive shaping of genomics data in cancer clinical trials**

In the spaces of convergence, knowledge production of genomics takes place through the multidisciplinary communicative and discursive processes between medical oncologists and genome scientists who have different epistemic cultures and styles of practice. This communicative process transforms genomic data from biological form into informational and technological form. Using the Social Construction of Technology (SCOT) approach (Pinch & Bijker, 1987), we learn that different social groups and

stakeholders built around the artifacts culturally and discursively construct technological artifacts such as genomic technologies in a 'multidirectional' model. Each social group or stakeholder has its own problems, and each problem has its own solution. This is where the spaces of convergence take place, which in turn creates a new wave of social relations. At the point of convergence, communication, discourse, and rhetoric take over. On a SCOT analysis, the understanding and the design of technological artifacts carry an *interpretive flexibility* in which the social construction of technologies are the result of rhetorical operations between the stakeholders of technologies, their uses, agendas, and solutions to their problems (Grint & Woolgar, 1997). The underlying mechanism for interpretive flexibility is made possible by the symbolic communication and facilitated coordination among the practices of the multidisciplinary cooperation between heterogeneous social groups (Duncker, 2001). This multidisciplinary cooperation co-constructs genomics to be a boundary object defined as "objects which are both plastic enough to adapt to local needs and the constraints of the several parties employing them, yet robust enough to maintain a common identity across sites" (Star & Griesemer, 1989, p. 393). This leads to the knowledge production of genomic information "taking place inside and outside of organizations and institutions that have ceased to fit within any clear categories" (Prainsack, 2012; Dove et al., 2012, p. 3). Following this logic, I could infer to genomic information as a boundary object traversed across different stakeholders by collaboration and communication among heterogeneous practices on equal terms, shaped by their problems and agendas, in turn leading to the meaning making of the information. Therefore, clinical cancer genomic trials like POG manifest the social construction of genomic technologies, as they represent spaces of convergence where the social and

discursive processes between different stakeholders shape the technologies and meaning-making of the information.

POG exemplifies the social and discursive shaping of the knowledge production of genomic information. POG is an interdisciplinary collaboration between physicians, medical oncologists, genome scientists, pathologists, bioinformaticians, medical geneticists, and social scientists from communication, bioethicists, and health economists. The group meets weekly to discuss two to four individual patient cases. There are three parts to the analysis. First, a MO presents an overall background of the patient, their current cancer treatment, and may ask the data analysts specific questions regarding the next therapy that would be standard for this patient. Second, a pathologist presents the tumor analysis of the cancer patient. Third, a bioinformatician/genome analyst presents genomic sequencing and a genomic pathway data and identifies potential biological pathways to be considered for a therapeutic intervention. The presentations are followed by a collective discussion and assessment for potential treatment strategy. This is different than commercial panel-based profiling tests in which more simplified versions of genomic analysis can be ordered by MOs, who then receive a report of genomic data that they must interpret for themselves. The POG meetings signify the communication culture of medicine where the meaning making of genomic results takes place through the social interactions, discussions, and communication of the multidisciplinary medical stakeholders.



**Figure 2. POG genomic sequencing data flow**

Amongst the medical stakeholders, researchers and practitioners tend to have conflicting perspectives on genomics. For instance, a bioinformatician may rely more heavily on what the genomic data shows, whereas a physician may be more skeptical about the clinical utility of the genomic data. This tension of knowledge and belief tends to happen at the POG meeting. From one of our observation notes on a discussion regarding a hypoxia (low oxygen) pathway, a scientist in the conference room expressed a sense of skepticism towards that particular pathway analysis provided by the bioinformaticians: “not sure if genomics is the best way to look at it but interested to see what you folks say”. Bioinformaticians look at data through a lens involving statistics and evidence in published journals. Therefore, their interpretations of a specific condition

may lack the precision of a wet lab scientist who has spent many years researching that specific pathway or a medical expert who has treated patients with the condition. This comment of the scientist indicates skepticism in genome sciences and a lack of equivalence in medical knowledge and expertise between different medical experts.

The asymmetry in medical knowledge can also result from a lack of communication between bioinformaticians and other medical specialists. At one of the meetings, the bioinformatic team presented their results of a gynecologic cancer. Through the POG meeting, it was determined the tumour sequence was compared to the wrong data set due to differences in the nomenclature of these specific cancers. Using the encoding and decoding model, this highlights challenges in using online databases where incorrect or misleading demographic or diagnosis information can lead to incorrect decoding of the data. In this case, the bioinformaticians needed to communicate with gynecology experts to ensure they understood how to analyse the data by identifying the correct datasets for comparison. Therefore, the communication, discourse, and rhetoric taken place between multidisciplinary medical stakeholders at the POG meetings can influence the decisions of medical oncologists whether or not to adopt genomic information into their clinical diagnosis, and shape the social structure through which genomic technologies diffuse (Green, 2004). Taken together, cancer clinical trials illuminate the communication and discursive processes in the spaces of convergence between multidisciplinary medical stakeholders to co-produce knowledge and meanings of clinical genomics data and determine the technological diffusion of genomics into clinical care.



## **Technological diffusion of genomics into medical oncology**

Clinical genomic trials make up a bioclinical collective of different medical stakeholders, and hence, they engender an asymmetry or a lack of equivalence in styles of medical reasoning and practice. Therefore, I argue that clinical genomic trials challenge typical processes of the traditional healthcare system as well as the traditional medical education. The emergence of genomic sequencing technologies, in a certain degree, echoes an anomaly of the discovery of X-rays in 1895. The invention of the X-ray was a classic case of discovery through an accident. Scientists were not only surprised but reluctant to welcome X-rays as a scientific discovery, mainly because X-rays challenged the previously ingrained normal science paradigms and expectations of laboratory procedures (Kuhn, 1996). Therefore, X-rays rendered a new approach to science that resulted in a paradigm upheaval in the core knowledge of science. WGS is experiencing similar diffusion processes as X-rays technology when it was first introduced. WGS, or other related genomic technologies such as transcriptome sequencing, has not yet been integrated into the mainstream healthcare system because they carry a lot of uncertainties and drawbacks. In 36 interviews with systems biologists from Europe, US and Japan, genomics is portrayed as a disappointment because “it failed to deliver, both in a socio-economic sense of providing cures for diseases, and in a conceptual sense of providing an understanding of the complexity of organismal function” (Calvert, 2013. p. 469). As a result, the mainstream healthcare system is reluctant or unable to adopt the genomic technology in applications they know and understand. Genomic technologies, like any

other technical innovations, have to undergo the innovation-decision process comprising of five interrelated stages before it can diffuse into a clinical system.

Roger's diffusion of innovations framework (2010) postulates that the process of adopting a new idea or innovation follows a bell-shaped curve over time to approach normality. The bell-shaped curve also divides itself into five different categories: innovators, early adopters, early majority, late majority and laggards. While innovators play a gatekeeping role in the introduction of new ideas into a system, early adopters are members with high prestige in society. The early adopters, who are also considered the opinion leaders, have greater exposure to mass media, greater social participations, higher socioeconomic status and more innovative than the general public. Communication channels play an indispensable role in determining the outcome of the innovation-decision process. Interpersonal channels, which involve face-to-face interaction or exchange between two or more individuals, are arguably more influential in the persuasion stage of forming favorable and unfavorable attitudes towards the innovation. This is because individuals can share their personal experiences and attitudes towards the innovation with each other. Furthermore, for a new technology to have an active dissemination and become a sustainable innovation, it needs to achieve five characteristics: (1) relative advantage - it needs to be better than its preceding technologies; (2) compatibility - it also needs to fit with its intended users; (3) complexity - it needs to be easy to use; (4) trialability - it needs to be tried before making a decision to adopt; and (5) observability - the results of the innovation need to be visible and easily measurable (Oldenburg & Glanz, 2008). Drawing upon this diffusion of innovation model, clinical genomics is still in early stages of adoption where the clinical

validity and utility still remain highly uncertain. There is a critical need to understand these early adopters. Practitioners at the clinical trial of POG represent the early adopters of this technology. And they ultimately make the decision on the success or failure of the adoption of genomics.

Genomic technologies offer exclusive insights and knowledge to rare cancers and acute disease that the traditional healthcare technologies fail to produce. Nevertheless, it is still too soon to know whether genomic technology will fit in with current healthcare systems. Today, scientists are learning more and more about genomics than they ever did in history. This overwhelming amount of new knowledge and data makes it very challenging to understand and apply genomics into clinical practices. Because genome sequencing is such a recent development, understanding a genome sequence is a highly specialized skill, such as a post-graduate Ph.D. in molecular biology, and doctors have not yet been well-trained in reading human genome code or data. Cancer clinical trials manifest the technological diffusion of genomics in which they offer interpersonal communication channels for forming attitudes and trailability for experimenting the technology. The innovators are genome scientists, and the early adopters are doctors, clinicians, and medical oncologists in clinical genomic trials. At the adoption stage, genomics is transitioning from data scientists to domain experts, which creates a disruption in styles of practice. This disruption engenders not only new medical knowledge, but also uncertainties and risks. In social dimensions of risk production and reception, disciplinary alignments and culture of professional practice profoundly shape how different stakeholders define, assess, and manage the risk and uncertainty of data (Pinch, 1986, Hilgartner, 2009). As such, genomic technologies render a new regime of

clinical systems converging genetics, molecular, biology engineering, and computational biology. Genomic technologies, like X-ray, produce a paradigm shift in understanding methods and treatments of human diseases. Moreover, this paradigm shift leads to a new upheaval of social relations in oncology practices. These social relations influence the construction and narratives of risks and uncertainties in genomic data.

## **General level of genomic knowledge amongst physicians**

In a recently published systematic review on perceived barriers of genetic services, Mikat-Stevens et al. (2014) pointed out that deficits in physicians' genomic knowledge, skills, and confidence are one the main challenges to the integration of genetic services into clinical practices. The result of this study highlights the need to understand the causes for a lack of genomic knowledge among physicians and strategies to overcome the gap in genomic knowledge and skills. Scholars conducted research in a number of national contexts including the United States (Christensen 2015), the United Kingdom (Westwood 2012), Canada (Telner 2008), Australia (Flouris 2010), China (Li 2015), or Kenya (Hill 2015), to understand the benefits and limitations of genomic literacy. I conducted a systematic review of genomic literacy among physicians to provide an up-to-date systematic review of perceived barriers in genomic knowledge and potential strategies for physicians to improve their genomic literacy. The objectives of the systematic review are to (1) examine the level of genomic knowledge, education, or practices amongst physicians; (2) assess the attitudes of physicians towards genomics; (3) evaluate the current status of genomic materials in medical school curricula; and (4)

identify potential strategies for development of genomic education among physicians. The goal of this systematic review is to provide a holistic and insightful view of the genomic knowledge, attitudes and practices among physicians in thinking about the benefits, risks and gaps in genomic research and technology.

I searched five databases from 1990 to 2015. Initially, the search yielded 1024 articles based on relevant titles and abstracts. After cleaning the data based on our inclusion criteria, I ultimately coded and analyzed 53 articles, with the oldest article dating back to 1993. As the volume and scope of genomic information increases in health care contexts, practitioners will require basic genomic literacy in order to obtain, process, understand, and use genomic information for clinical decisions. Twenty-five of fifty-two reviewed studies reported on the general level of genomic knowledge amongst physicians. The systematic review covered a wide time range in hopes of identifying a change in levels of genomic literacy with time. However, the general level of genomic literacy identified in the reviewed studies across the twenty-five year time frame remains stagnant. Many studies found a lack of genomic knowledge among physicians, which resulted in the limited application of genetic information into clinical practices due to lack of confidence in their genomic knowledge. For example, a study conducted by Nippert et al. (2011) sampled 3686 physicians from five countries in Europe and found 44.2% are not confident, 36.5% are somewhat confident, and 19.3% are confident or very confident in incorporating genetics into their clinical practices. Over half of physicians indicated they are confident incorporating genetics into clinical practice. This is an encouraging result considering the majority of the studies in the review population over time reported positive confidence levels less than 50%. It also indicates there is a

significant portion that needs to understand the science and its application better. The authors also point out a positive correlation between level of genomic confidence and exposure to medical genomic education or training.

Few studies used recent graduation from medical school as an indicator or predictor of genomic knowledge (Li et al., 2014; Acton et al., 2000; Hofman et al., 1993). The rationale behind this particular predictor is that medical schools seem to be including more genomic and genetic training in the curriculum than in the past due to the rapid expansion of genomic science. Hofman et al. (1993) designed a facts and concepts questionnaire validated by geneticists and genetic counselors, and found recent medical school graduates tend to have a higher mean knowledge score than those graduating earlier. The result was supported by a survey study of 1,148 physicians, Acton et al. (2000) identified that “physicians in practice ten years or less were more confident than were those practicing more than 20 years in explaining genetic test results to patients ( $p = .01$ ) and in tailoring recommendations for screening based on genetic test results ( $p = .02$ )” (p. 851). In 2015, a study published by a group of researchers in China identified similar significant associations between high knowledge scores of genomic testing with more recent entry into medical workforce or recent graduation from medical school.<sup>11</sup> The study reported that significant associations with higher personal genetics knowledge score were “more recent entry into medical workforce ( $P=0.047$ )”, and “recent genetics training ( $P=0.035$ )” (Li et al., 2014, p. 759).

These studies indicate physicians who graduated later from medical school tend to have higher knowledge and confidence than those who graduated earlier. It is reasonable to expect level of genomic literacy to change over the last ten years with the proliferation

of genomic research and rising interest in clinical application in the biomedical community. However, recent studies still show a deficit of genomic knowledge among physicians (Gray et al., 2014; Christensen et al., 2015; McGowan et al., 2014; Li et al., 2015; Nippert et al., 2011, Houwink et al., 2011, 2012; Nickola et al., 2012; Selkirk et al., 2013). In a recent study, Christensen et al. (2015) explored whether primary care physicians (PCPs) and cardiologists feel they are ready for whole genome sequencing. The authors found that while PCPs are generally concerned about their understanding about genomics, cardiologists are more particularly concerned about how to interpret specific types of genomic results and incidental findings unrelated to their specialty. Physicians also appear underprepared or inadequately prepared to incorporate pharmacogenomics or personalized medicine in their clinical practice as a result of the lack of pharmacogenomics content in the professional education curricula (Nickola et al., 2012; Selkirk et al., 2013). Based on Figure 1 in Selkirk et al. (2013) study, 14% of their surveyed physicians reported “above average to expert knowledge” and 52% had “no to minimal knowledge” about pharmacogenomics. These types of sentiments manifest biomedical and social disruptions of genomics in health care and medical education, considering the rapid advancement of genomic technologies. Overall, it is clear that there is an existing genomic literacy gap amongst physicians that we need to address. The lack of genomic literacy among practitioners poses challenges for the transition of genomic technologies into clinical care, as well as calls into question the knowledge production of genomic information that can have tremendous effects on patients’ well-being, vitality, and subjectivity. As a result, the research questions of this thesis are:

## **Research Questions**

**Research Question 1:** What is the general level of genomic literacy among medical oncologists in BC?

**RQ1a:** How is current medical school curriculum preparing medical oncologists with genomic education or training?

**RQ2:** What are the perceived values of genomic technologies among medical oncologists in British Columbia?

**RQ2a:** What are the perceived values of POG among medical oncologists in BC?

**RQ3:** How does communication and discourse processes between different medical specialists influence meaning making of genomic information in cancer clinical trials?



## Chapter 3.

### Methodology

With government funding sources such as GE<sup>3</sup>SL research to investigate the social implications of genomics, social study of genomics is a fruitful field of research in Canada. Many Canadian researchers study the social, political, and cultural aspects of genomics, most particularly genotype (Bubela & Caulfield, 2004; Caulfield, 2004; Bubela et al., 2009), research ethics of whole-genome sequencing including the issues around informed consent and biobanks (Caulfield et al., 2003; Caulfield, 2007; McGuire & Caulfield & Cho, 2008; Caulfield & Kayet, 2009), public trust and perceptions of biotechnology (Caulfield et al., 2006), the use of informed consent in genomic research (Chow-White et al., 2014), the informatization and digitization of race (Chow-White, 2012; Nakamura & Chow-White, 2012), and the interconnected relationship between big data and genomic technology (Frizzo-Barker & Chow-White, 2014; Chow-White et al., 2015). Other researchers focus more on the issue of genetic discrimination (Bombard et al., 2007, 2011; Oster et al., 2009; Otlowski & Taylor & Bombard, 2012), public or patients' perceptions of personalized medicine (Bombard et al., 2014a), and the use of genomic technology in treating cancer (Bombard et al., 2014b). While all of these research areas constitute a large part of the social studies of genomic science, there is a lack of research in Canada to study the knowledge translation of genomic technology or research into clinical practice. One of the biggest challenges in the process of transitioning genome sequencing technology into healthcare setting is a lack of genomic literacy to handle the massive volume of data generated by whole genome or exome

sequencing (WG/ES) (Bombard, 2015). Resulting from a lack of genomic literacy, physicians fail to accurately and efficiently interpret genomic data or identify clinical utility and validity of genomic information. Therefore, it is important to assess genomic literacy of physicians, who are the principal users of the WG/ES and other genomic technologies in cancer treatment. In Canada, there is no current research to examine the level of genomic knowledge among physicians. As a result, there is a need to conduct our own empirical study to explore the genomic literacy among medical oncologists in British Columbia.

This thesis is a collaborative project, funded by Genome BC, in affiliation with BC Cancer Agency in order to measure genomic literacy, attitudes, and experiences of medical oncologists working with POG. In another word, this thesis is a co-production between scientists and medical specialists at POG and social researchers at the GeNA Lab under the direction of Dr. Peter Chow-White. For this project, we co-constructed a survey based on semi-structured interviews, consultations, and validity check with medical specialists at POG. This survey functions as a user exit survey aiming for oncologists, who are the domain users of the genomic technologies and data. The main goal of this survey is to identify the potential values and challenges of applying genomic technologies into clinical practice in the context of cancer clinical trial at POG. The project aims to produce fruitful results to understand and better advance the technological diffusion of genomics into clinical care. This methodology chapter will outline the process and rationale of designing our survey instruments including semi-structured interviews with project principles at POG, literature review on other similar survey protocols, survey design, pilot survey, data collection, and data analysis.

## **Semi-structured interviews with POG project principals**

As mentioned earlier, the survey was a collaborative project with Genome BC in affiliation with BC Cancer Agency to measure the experiences of medical oncologists with POG. Therefore, it is extremely important to include the interests and agendas of the project principals of POG in the survey. Although interview is not the main method to collect actual findings, we conducted semi-structured interviews with five project principals from POG to identify their interests for the design of the survey questions.

Semi-structured interviews are less formal and rigid than structured interviews. They are more conversational about a specific topic than a structured interview with a strict protocol (Croucher & Cronn-Mills, 2014). In a semi-structured or unstructured interview, the majority of the questions are structured in a flexible interview protocol in order for the researchers to make the interview more open and fluid. Also, with semi-structured interviews, researchers are more flexible to build rapport with the participants in order to gain an in-depth understanding of the topic or subject (Briggs, 1986; Croucher & Cronn-Mills, 2014). Researchers often employ semi-structured interviews when they are open to having participants shape their understanding and approach to the topic. Geertz (1973) called the open and flexible expressions of thoughts as thick description - “an in-depth understanding of a culture or setting provided by the members of the culture and captured by others (researchers and journalists)” (Croucher & Cronn-Mills, 2014, pp. 159). The goal of the interviews with the project principals of POG is to understand their thoughts and interests, and employ those ideas into developing our survey questions. As a

result, this semi-structured interview is the first and foremost step in designing the survey.

The findings from the interviews were instrumental in the writing of the survey questions. Applying the co-construction approach, we requested interview with five different medical stakeholders of POG including three medical oncologists, one bioinformatician, and one genome scientist. We conducted three interviews in person and two interviews over the phone. Each interview took around half an hour to an hour depending on our interviewee's schedule. Before asking any questions, we explicitly explained to them the informed consent and requested their permission to record their responses and use them for our study. Since these were semi-structured interviews, each interview transcript is different from each other, as we did not have an interview protocol with a fixed set of questions. We applied Kvale question types such as follow-up questions, probing questions, specifying questions, and direct questions to make sure the interviewee did not go off the topic too much and we could still get the information we needed. As a result, we gained useful information for the construction of the survey. Although different interviewees have different perspectives on what they want to know from the POG survey, those perspectives are inter-correlated with each other. The main interests they want to find out from POG survey include four main themes: (1) the clinical values of POG in which whether POG help change their decision-making process or management plan for their cancer patient treatment; (2) the oncologists' expectations when coming to POG and their experiences after collaborating with POG; (3) the knowledge or understanding about genomics among the oncologists; and (4) the communication process of POG.

## **The rationale for survey design**

Through our extensive literature review and systematic review of literature examining genomic knowledge of physicians, survey is the most widely-used method to measure genomic literacy among practitioners. The advantage of survey, especially self-administered ones, is its flexibility in time. Our sample consists of medical oncologists whose schedules are extremely busy and hectic. With an online survey invitation, the oncologists can choose to fill in the survey at any time. Furthermore, survey results are easier to code and compare between different answers from different respondents (Neuman & Robson, 2015). Survey data can be flexible to analyze, since surveys allow us to develop operational definitions from actual observations (Babbie & Benaquisto, 2014). However, surveys lack the ability to gather descriptive and in-depth data such as interview data, and the ability for researchers to probe questions according to the responses. Moreover, some level of measurements in survey research can be very subjective and ambiguous. Nevertheless, surveys have strong reliability, which refers to the ability to replicate the results or the findings under identical or similar conditions. That is a major benefit of survey research for the study, because we could design our survey protocol based on other similar surveys. We could also examine the reliability of other surveys and compare and contrast our study results with others to enhance the generalizations of our findings.

One of the two main survey approaches used to measure genomics knowledge is testing basic and advanced concepts of genomics with different knowledge tests (Hofman et al., 1993; Escher & Sappino, 2000; Kolb et al., 1999; Wideroff et al., 2005). For

example, Wideroff and colleagues (2015) designed three knowledge questions about BRCA1/2 paternal inheritance, percentage of breast cancer patients with BRCA1/2 mutations, and penetrance of HNPCC mutations to assess hereditary breast/ovarian and colorectal cancer genetics knowledge among physicians.

The other popular survey strategy is letting physicians subjectively evaluate their genomics knowledge, confidence, attitudes, educational needs, or experiences using genomics in their clinical practices (Burke et al., 2006; Fry et al., 1999; Gray et al., 2014; Acton et al., 2000; Flouris et al., 2010; Hayflick et al., 1998; Leitsalu et al., 2012; Nippert et al., 2011; Watson et al., 2001). For instance, in a study examining genomic confidence among physicians, Nippert and colleagues (2011) designed Likert-scale questions for self-assessed confidence in physicians' ability to carry out basic medical genetic tasks. The study found from a sampling frame of 139,579 physicians that 44.2% of them are not confident in incorporating genetics into their clinical practices. The advantage of the first survey approach is that it can yield more accurate and objective results of genomic knowledge of participants. However, a limitation for this approach is that participants might be reluctant to take a knowledge test. This can discourage respondents from participating or cause them to drop the survey at any time they find it too challenging. On the other hand, for the second survey approach, even though it might yield more subjective results of genomic knowledge, it makes the questions easier for the respondents to answer. For our project, a project principle at POG advised us not to set up a knowledge test in our survey as that will discourage our respondents. Therefore, we followed the second survey strategy and designed Likert-scale questions to allow MOs to self-assess their level of knowledge, attitudes, and perceived values of clinical genomics.

We constructed the survey questions based on other similar survey protocol. The first and foremost survey protocol is the “2011 Physician Education Survey” conducted by researchers from UBC. About 40% of our questions were actually based off this questionnaire. The questionnaire aims to capture the educational needs of physicians on genomic knowledge. It comprises five sections: demographics, research, education, knowledge and impact. It covers a wide range of topics from how a physician would like to update or educate themselves on genomics to how much knowledge they have in specific topics related to genomic, and how important they think genomic science and technologies are to their practice. One of the limitations of this survey is the ambiguity of the Likert-scale questions asking the respondents to self-rate their level of knowledge or their perceived importance of genomic technologies on a Likert scale from 1 to 5. Different respondents can have different interpretations of each scale. To overcome this limitation, we used the scale of “no knowledge, little knowledge, knowledgeable, very knowledgeable, and expert”. In this way, we also eliminated the “neutral” option and put the respondent in a position where they actually have to make a decision on their level of knowledge. This survey is extremely valuable to the question design, because it does not only discuss the genomic knowledge and education topic, but also explore the values of genomic technologies among physicians who are the frontline of healthcare systems.

Another significant survey protocol is the “Ethics and Genomics Survey” from Genomics England. This web-based survey was designed by researchers from the Wellcome Trust Sanger Institute Cambridge UK as part of the Genomethics social sciences project (Middleton et al., 2016). The scale of this survey is massive. It received almost 7000 responses from 4,961 members of the public, 533 genetic health

professionals, 843 non-genetic health professionals, and 607 genomic researchers from more than 75 countries around the world. The major goals of this survey is to examine, from the public's perspective, their preferences on receiving incidental findings of their genomic information; and from the health professional's' perspective, their thoughts on returning incidental findings to their subject participants. The unique element about this survey is that for each section of the survey, there is a short video accompanied with the questions explaining and illustrating what the subject is about. This survey consists of five main parts including demographic background, sharing incidental findings, relations with risks and how to handle raw data, duty of genomic researchers, and consent for genomic research. The most relevant section of this survey is on how to handle raw genomic data. When the oncologist registers his or her patient to POG, depending on the cases, POG runs a panel sequence or whole genome sequence of the patient to identify the tumour type and the genomic pathway. One of the sections in the survey is to find out whether the oncologists could understand and communicate the results back to their patient and apply that data into their decision-making process. Genomic literacy plays a key role in this task. If the oncologist has little knowledge about genomics, he or she will face a major challenge in understanding and applying the results into their clinical practices. This survey provides a major framework for the survey including the demographic background and genomic knowledge sections.



## **Study Design and Measures**

After carrying out unstructured interviews, extensive literature review and systematic review, we collected many useful information to construct the survey questions. Yet, the survey protocol still went through one pilot survey and ten times of revisions before we officially finalized all the questions. In the first version, the questions were categorized into three sections including contact and experiences, genomic impact and space of convergences. The contact and experiences section mostly covered background information of the respondents and their clinical practice experiences. Under the genomic impact theme, the questions tried to measure the importance of genomic technologies in their clinical practices along with the harms and benefits genomic technologies bring to our respondents. The last section was called “spaces of convergence” because genomic science is an interdisciplinary field, which brings together scientists, social researchers and other stakeholders in the research and translation of genomics. It is spaces of convergence between different groups and different stakeholders, which force them out of their comfort zone to work together and produce new medical knowledge. As a result, in this section, we tried to assess the genomic knowledge of our respondents and their perceived values about POG. This version of the survey was short, but adequate and efficient. However, the questions were not detailed enough to target all our interests.

For the later versions, we input more questions, which are relevant to the main themes of the survey in order to expand the scope of it. For example, in the demographic information, we added questions related to oncologists’ years of practicing, their location

and approximately how many cancer patients they have per year. The demographic information data acts as our independent variable for future bivariate analysis. Our dependent variables include our respondents' current knowledge of genomics, their use of genomics in oncology, and their experiences with POG.

The final survey consists of three main sections: (1) genomic knowledge and education, (2) clinical genomics in oncology, and (3) experiences collaborating with POG. In the current knowledge of genomics section, we asked our respondents to self-rate their knowledge of three items related to genetics/genomics from no knowledge to expert level. This section also examined their perceived importance of improving their genomic knowledge. In addition to that, we asked the respondents how they typically update their own genomic knowledge and whom they think should be responsible for updating physicians about genomics. Most importantly, the questions also tried to identify whether the respondents think the current medical curriculum is well equipped with enough genomic training or education for future health professionals.

The following section "clinical genomics in oncology" focuses on the impact of genomic technologies on their clinical practices. This section asked the respondents how often their patients ask about using genetic analysis to aid in diagnosis or treatment, or if any of their patients have used direct-to-consumer genetic testing. The goal behind these two questions is to learn the public perceptions of genetic or genomic testing and its impact on our oncologists' practices. We also asked our respondents to predict the impact that genomic technologies would have on their practices in the next five years, whether they would apply genomic technologies more frequently, and whether the technologies would have a major or minor impact on their practices. Aside from the positive impact,

we also tried to measure the concerns our respondents have for the use of genomic technologies such as the clinical usefulness of the data, cost, immaturity of genomic science and technologies, and the dilemmas of returning incidental findings.

The last section of the questions aims to examine the experiences and perceived values of our respondents for POG. In this section, the questions aimed to explore their goals in partnering with POG and the impact of POG on their clinical decisions regarding the cancer treatment of their patients. We asked our respondents if they have any concerns with the recommended treatments suggested by POG. In the end, our respondents were asked to rate their satisfaction level with POG, and whether they would collaborate with POG again. Subsequently, we asked our respondents whether they think POG should be funded by the provincial government, and explain their choice. These last two questions are the most important ones in the whole survey. The organization of the questionnaire and the order effects of the questions were set up to lead the respondents to the last two questions with a clear judgment and thorough reflections on the three main elements: their genomic knowledge, the use of genomic technologies in their oncology practices, and their experiences in partnering with POG. This flow of the survey questions could allow them to evaluate objectively whether POG should receive public funding from the government. Our initial expectation for this response was “yes POG should receive public funding”, but the pilot result for this question was an opposition response.

After completing the writing of all the questions, the research team at GeNA lab showed the draft questionnaire to one of the project principals from POG that we interviewed to get a scientific validity check. As social researchers with no formal

training in medical and genetics sciences, we cannot assure that the materials asked in the questionnaire are scientifically correct. Therefore, we need a medical expert to examine the scientific validity of the questions. As a medical oncologist, the project principal provided many useful feedback and critiques for different parts of our questions either related to the inaccuracy of the questions or the scientific validity of the questions. With that significant feedback, we did another round of revision for the survey to ensure all the questions are coherent and scientifically accurate. That is also the final version of the survey (see Appendix A for the survey protocol). Taken together, to construct this survey, we conducted a large-scale literature review, a systematic review, multiple times of revisions, and facts and concepts check with a medical expert to assure the scientific validity for the survey.

## **Data collection: challenges in getting responses from oncologists**

### **Target population**

This thesis is a part of a collaborative project with POG in examining the values of POG, and therefore, the target population is medical oncologists, who have collaborated with POG by enrolling their cancer patients in clinical trial studies at POG in hopes of finding an effective treatment for their patients. Medical oncologists belong to an elite and hard-to-reach population due to the demanding nature of their work and their high professional status in social hierarchy (Flanigan et al., 2008). They also represent the opinion leaders in society and the early adopters in the Everett Rogers' *diffusion of innovation* model. Hence, they are one of the most frequently approached population

groups for surveys or other empirical research, which makes them more reluctant to participate. It is also not easy to approach them at the first place because you would normally have to go through their secretary or other gatekeepers to get in touch with them. Emailing can be the fastest way to contact them, however, their email inbox is usually flooded with other emails. As a result, response rates with physicians or clinicians are average about 10 percent lower than that with general population (Cummings et al., 2001; Flanigan et al., 2008). In fact, I faced this particular challenge in the data collection process for the survey.

### **Data collection**

The number of oncologists enrolled in POG continues to grow over time. At the time of sending out the survey, our target population size was 59. One of the main project principals at POG sent out email invitations to all the oncologists currently enrolling in POG on October 23rd, 2015. The project coordinator at POG also sent out several follow-up emails after that. However, over the course of four months, I only received nine responses. This data particularly shows how difficult it is to get oncologists to fill out a survey. As a result, I needed to employ some other recruitment methods to improve the response rate considering that the nature of our population is a group of very busy doctors. Tambor and his colleagues (1993) addressed the issue of response rate based on their large-scale survey study on physicians' knowledge of genetics. They randomly selected physicians and offered \$25 incentive and intensive follow-up in their final survey to increase the response rate. It turned out that the response rate from physicians in the final survey was 64.8% (n =1140) compared with 19.6% in their pilot test. Another

research done by Flanigan and his colleagues (2008) in reviewing survey literature published from 1987 to 2007 also focused on how to conduct survey research among physicians and other medical professionals. They also found that offering prepaid incentives were the most effective. In addition, preparing a personalized cover letter addressing directly to the physician could also really help increase the response rate. Postcard reminders, telephone “prompts”, and email or fax “prompts” were also effective in increasing their response. Most importantly, they recommended researchers to keep the length of the questionnaire short and concise, because physicians are usually very busy and they can get discouraged with longer questionnaires.

To recruit more respondents, the research team tried to employ all the findings above such as offering a prepaid incentive, doing survey promotion at POG meeting, or conducting intensive follow-up. However, a project principal at POG advised that oncologists, whose income are usually much higher than that of average person, are not interested in monetary incentives. It is a lack of time or interest that impedes them from answering the survey. After four months of passively waiting for responses, we decided to be more active and assertive in approaching the target population. We designed a personalized email invitation addressing directly to each oncologist asking him or her politely and kindly to complete the survey. In the personalized email, we also offered to conduct the survey with them on the phone. Shortly after sending out the personalized email, the response rate increased significantly from 9 to 20 responses in about one week, and one oncologist accepted the phone survey offer. After that, the response rate stayed idle until we sent out a round of personalized follow-up emails. Furthermore, we even actively contacted 15 oncologists’ office by phone calls, but only got to speak to their

secretary. We then sent their secretary personalized reminder email, hoping that the secretary would bring up the survey to their attention. After a long recruitment process, the survey finally achieved 31 responses, which reaches a ratio of 52.5% response rate.

## **Data analysis**

To recapitulate the method section, the study was conducted from April 2015 to April 2016 and consisted of unstructured interviews of five project principals at POG and a cross-sectional survey of 59 oncologists (a hypothesized representative sample based on the following assumptions: skewed distribution, purposive sample and small population) who collaborate with POG by enrolling or intending to enroll their cancer patients in clinical trial studies at POG. After five months of recruiting participants, the survey received 31 responses (52.5% response rate). Each response was input into an Excel spreadsheet for logging and tracking purposes. Categorical response frequencies were analyzed to report the descriptive statistics. Conceptually related sets of rating scaled responses were subjected to within-subjects repeated measures analysis of variance (ANOVA) to test the differences in mean scores of different attributes under the same variables. The analysis also performed inferential statistics between gender, location, years of practicing oncology and number of cancer patients as independent variables with the level of genomic knowledge and POG values as dependent variables. Only the analysis using physicians' location produced some consistent and meaningful patterns or associations of results. Due to the relatively small sample, instead of using  $\chi^2$ , the survey used Fisher exact tests to examine the statistical significance of the findings. The next chapter presents participant characteristics and findings on their level of genomic

knowledge, which answers RQ1 and RQ1a. Chapter 5 discusses the findings on the attitudes and experiences of the MOs working with clinical genomics to address RQ2, RQ2a, and RQ3.



## Chapter 4.

# **Genomic literacy among physicians: examining technological diffusion of genomics into clinical care**

## **Background**

Medical practitioners are increasingly dealing with genomic big data in their research and clinical work. Genomic data helps scientists understand the molecular causes of diseases (Martin-Sanchez & Verspoor, 2014). Genomic sequencing technologies are on the horizon for the treatment of patients in recent years, particularly in oncology (Nelson et al., 2013). Since the completion of the Human Genome Project (HGP) in 2003, scientists have promoted a genomic revolution in which genomics would create radical breakthroughs in scientific and biomedical practice. However, despite massive funding and research by both public and private agencies for several decades, clinical application of genomic technologies is still facing many risks and hurdles (Khoury et al., 2007). One of the main challenges in adopting genomic technologies into clinical practices is a lack of genomic literacy among healthcare professionals.

Physicians often report their level of genomic knowledge is inadequate in order to make treatment decisions based on a patient's genome sequencing information (Gray et al., 2014). Doctors and other front-line health professionals need access to better genomics knowledge and training in order to incorporate and apply this new information and technology into patient care. However, empirical research suggests that there is a dearth of genomic education in their medical education, training, and application among physicians (Burke et al., 2006; Hofman et al., 1993; Metcalfe et al., 2002; Wideroff et al.,

2005). Overall, genomics materials are not thoroughly incorporated into medical school training. For example, Julian-Reynier & Arnaud (2006) surveyed websites and published or unpublished documents of undergraduate medical education (UME) programs in France. The study found that genetics training in UME and Continuing Medical Education (CME) was taught by a limited number of university professors and not considered a priority. Thurston et al. (2007) found similar trends in North America in a survey with 149 American and Canadian medical genetics course directors and curricular deans. The results pointed out that genetics were mainly taught in the first year of medical school but decreased in the third and fourth years. A recently-published study supported these findings in which the authors also found that “the mean number of total contact hours for genetics (including biochemical genetics) is 36 hours” with genetics content mainly being taught in the first two years and declining in the third and fourth year (Plunkett-Rondeau et al., 2015). In the U.K., Burke et al (2009) found that a majority of the family practitioners (73%) received either one day or one week of genetics education in their undergraduate training. Furthermore, 78% of their respondents reported that they could not recall covering any genetics topics in postgraduate training. Zhou et al. (2014) identified a similar trend at the global level. They found 34.4% of the clinically active members of the Human Genetics Society of Australasia (HGSA) agreed that their professional training in medical school had not prepared them to discuss genetic information with patients.

The advancement of genomics into clinical practice and the public sphere has promoted the need for all clinicians to increase their genomic literacy. An important step in addressing this need is to understand what physicians know about genomics. This

chapter investigates the level of genomic literacy, education, or practices among medical oncologists at POG. Understanding the genomic literacy among the practitioners at POG could unveil the opportunities and challenges in the technological diffusion of genomics into clinical care. Genomic literacy can also incite the knowledge production of genomics through multidisciplinary collaboration in spaces of convergence of cancer clinical trials. The findings in this chapter support one of the central arguments of this thesis, which genomics produces a new style of practice in oncology, requiring new models for genomic education and training. Cancer clinical trials operate not only as a clinical site for experimenting clinical genomics, but also an innovative milieu for social interactions, discussions, and communication between different medical stakeholders to learn and co-produce knowledge of genomic information. This co-production in experimental clinical trials like POG articulates genomics with a sense of hope and promises for personalized cancer diagnosis and treatment, as well as sociotechnical imaginaries constituted by the social orders of science, technology, and society.

## **Participant characteristics**

The results showed almost equal gender distribution between female (n=15) and male (n=16) physicians (Table 1). Other independent variables were their years of practicing oncology and their number of cancer patients per year in order to get a sense of their oncology experience. I used central tendency measurements of median for our ratio variables of “years of practicing oncology” and “number of cancer patients per year” to equally distribute the data for these two variables into two groups divided by their

median. The median for “number of cancer patients per year” was 180, so we grouped the responses into two groups of less than or equal to 180 or more than 180 patients per year. Likewise, the median for “years of practicing oncology” was 12, which coincidentally matched with the number of years since the Human Genome Project (HGP) was completed. Based on the impactful discoveries of the HGP, it could result in a paradigm shift in medical research and in styles of thoughts between physicians who had been practicing before and after the HGP. Locations where physicians practice are also an important factor to take into account. The majority of our respondents (n=13) worked in Vancouver Centre, and the rest worked outside Vancouver.

**Table 1. Demographic characteristics of our population**

<b>Variables</b>	<b>Frequency</b>	<b>Percentage (%)</b>
<i>Gender</i>		
Female	15	48.4
Male	16	51.6
<i>Years of practicing oncology</i>		
<= 12 years	16	51.6
> 12 years	15	48.4
<i>Number of cancer patients in the past year</i>		
<= 180 patients	18	58.1
> 180 patients	13	41.9
<i>BCCA location</i>		
Abbotsford Centre	3	9.7
Fraser Valley Centre	9	29
Southern Interior	5	16.1
Vancouver Centre	13	41.9
Vancouver Island	1	3.2

## **Levels of genomic knowledge and education in medical schools**

The first part of the survey explored physicians' perceptions and level of knowledge about genomics. We asked our participants to rate their level of knowledge based on a scale of 1 = 'little knowledge', 2= 'knowledgeable', 3= 'very knowledgeable', and 4= 'expert' on three different topics of genomic science and technologies: (1) basic genetic principles (ie., inherited patterns), (2) newer genetic/genomic technologies (ie., high-throughput sequencing, genotyping and copy number variation analysis), and (3) the process of whole genome sequencing or WGS (ie., features, eligibility criteria for sequencing, benefits, risks, and non-medical implications). The results showed the

majority of the physicians ranked themselves as knowledgeable (57%) or very knowledgeable (33%) (mean = 2.36; SD= 0.66) about the topic of basic genetics principles (Table 2). 7% of the physicians claimed that they have little knowledge. However, the results shifted as more and more physicians acknowledged that they have little knowledge about newer genetic technologies (50%) (mean = 1.61; SD = 0.67) and WGS process (41%) (mean= 1.77; SD= 0.76). Only one physician considered him or herself to be an expert on the field of basic genetics principles and whole genome sequencing process, and no physician regarded themselves as an expert in newer genetic technologies. 45.2% of the respondents did not have enough information and knowledge to understand the POG meeting and results (Table 7). 32.3% of them did not feel confident that they could communicate POG results to their patients (Table 7). As a result, the majority of our respondents had little or adequate knowledge about genomics (mean = 1.61-2.35; Item main effect  $F(1.5,46)= 30.7, P < 0.0001$ ). As a result, the majority of the respondents were knowledgeable to very knowledgeable about basic genetics principles. However, the knowledge scale shifted towards little knowledge and knowledgeable as the topic focuses on the more advanced genetic or genomic topics such as newer genetics technologies and whole genome sequencing. While this survey depends on self-rating knowledge scales, other studies measure the level of genomic knowledge by actual knowledge tests of basic and advanced concepts of genomics, (Hofman et al., 1993; Kolb et al., 1999; Escher et al., 2000; Metcalfe et al., 2002; Wideroff et al., 2005). However, this survey is based on the nature of voluntary participation in respondents. A knowledge test survey could discourage the participation of physicians, as it takes longer time and more thinking effort to complete. Furthermore, other data points in our survey

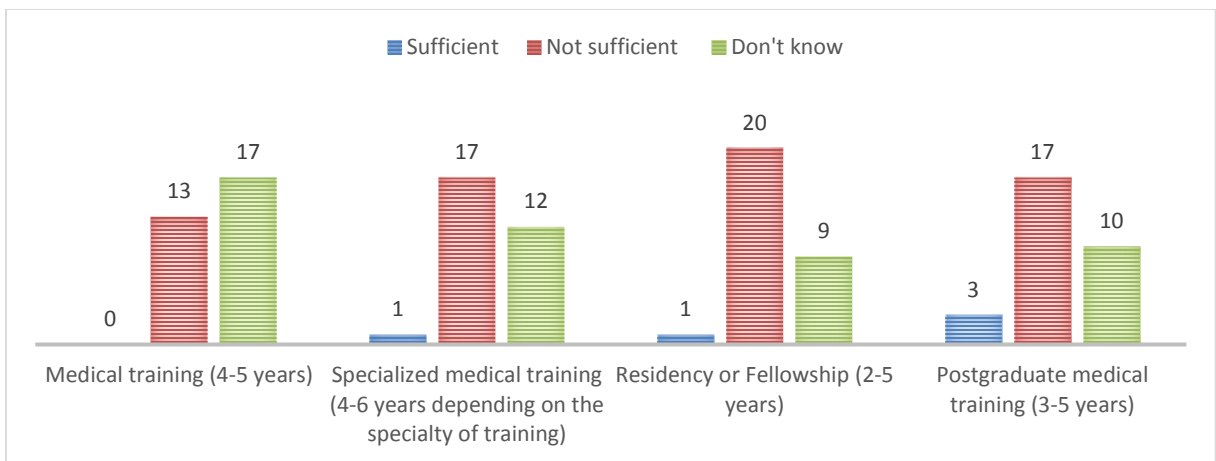
could also support the finding about the low level of genomic knowledge among physicians.

**Table 2. Physicians' level of genomic literacy**

<b>Genomic literacy</b>	<b>Little knowledge (%)</b>	<b>Knowledgeable (%)</b>	<b>Very knowledgeable (%)</b>	<b>Expert (%)</b>	<b>Mean (SD)</b>
Basic genetic principles (i.e., inherited patterns)	6.45	54.8	35.5	3.2	2.36 (0.66)
Newer genetic/genomic technologies (i.e., high-throughput sequencing, genotyping and copy number variation analysis)	48.4	41.9	9	0	1.61 (0.67)
The process of whole genome sequencing (i.e., features, eligibility criteria for sequencing, benefits, risks, and non-medical implications)	38.7	45.2	9.7	3.2	1.77 (0.76)

The survey asked the respondents to rate the sufficiency level of genomic education and training in medical schools. Even though the majority of our participants graduated from medical schools at least 5-10 years ago, many of them are professors in medicine and genetics or supervising medical students at a local medical school and are familiar with the current medical school curriculum. The results showed that the majority of our respondents either don't know (54.8%) or think medical training (4-5 years)

program did not sufficiently (42%) prepare students with enough genomic materials or training. Likewise, the majority of the physicians also thought there was not enough genomic training during their specialized medical training (54.8%), residency or fellowship (67.8%), or postgraduate medical training (58%) (Figure 3). This finding was generally consistent with the results Burke et al. (2006), in which 71% disagreed or strongly disagreed with the statement "the training that I have received in genetics has been sufficient to prepare me for work as a GP." (p.112)



**Figure 3. Sufficiency level of genomic education or training in medical schools**

## **Challenges in knowledge translation of genomics into clinical practice**

The lack of genomic literacy among MOs impedes the knowledge translation of genomics into clinical care and challenges the ability of physicians to interpret, understand, and apply genomic data into their practices. In one of our semi-structured interviews, an oncologist acknowledged that clinicians at POG usually have to rely on the



knowledge and expertise of bioinformaticians to analyze, organize, and filter out unnecessary information of genomic sequencing data:

I think the bioinformaticians have better ideas of what [information] we're looking for. Like in the beginning, I think they just grabbed [all sequencing data] and throw it out there and try to rank things. And we would look at it and interpret it differently based on our understanding of the technology. The bioinformaticians have better understanding of the technology overall, but I think we also got better and we are at the middle now. So some of the estranged noises are willed out. So I think that's more experience. (an oncologist)

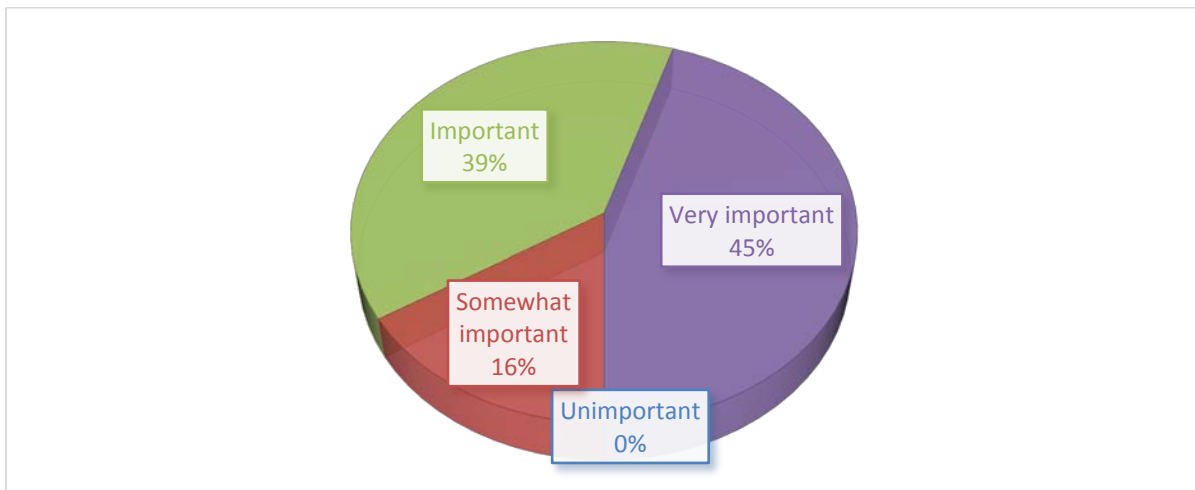
Reflecting upon another stakeholder's perspective, a bioinformatician had a different approach to genomic data. While a bioinformatician thinks all genomic data are informative, a clinician is more skeptical on the clinical utility of it:

There are some differences, maybe more genetics side. If we see a mutation in a gene that makes up a tumor type, but the precise mutation hasn't been seen before, clinicians will have skeptics for it, but bioinformaticians like us will think it has clinical utility. We're able to make correlation with bioinformatically with the tumor. Clinicians can say it's not relevant. (a bioinformatician)

Despite sharing similar clinical objectives, bioinformaticians and clinicians are two distinct professions with the former focusing on data algorithms and specialized computer software to solve biological problems at the molecular level, and the latter lacking computer skills to analyze and understand genomic data. Drawing upon a medical genetics scientist, while genome scientists and doctors collaborate on clinical projects, they also engage in debates about the scientific validity of genomic variants and their clinical utility:

That's a huge thing because these [clinicians], none of them are trained in medical school to think about genomic and only rarely is a medical doctor skilled in the art of genetics. Medical geneticists are a different department. So we need to embrace research as part of cancer care. (a medical genetics scientist)

These sentiments shown from an oncologist, a bioinformatician, and a medical geneticists illustrate a lack of equivalence or a lost-in-translation in the skills and knowledge between these multidisciplinary medical stakeholders. The long-standing traditional of medical education for MOs or PCPs does not comprise high-level training of genomic literacy. Therefore, MOs need to collaborate with other medical stakeholders including bioinformaticians and medical geneticists in order to translate genomic information into useful medical knowledge. This in turn generates a new style of practice in medical oncology.



**Figure 4. Importance level of improving genomic knowledge**

### **Importance of genomic education**

Due to the lack of genomic literacy and the difficulties in translating genomics into clinical care, the survey explored how important it is for physicians to improve their

knowledge of clinical applications of genomics science and technologies by asking them to rate on a scale of 1= 'unimportant', 2 = 'somewhat important', 3= 'important', and 4= 'very important'. The data showed that 45% of our respondents (n=14) considered it very important to improve their genomic knowledge (Fig. 4). Another majority of our respondents (39%) only thought it was 'important' to improve genomic knowledge. Even though none of the physicians consider updating their genomic knowledge unimportant, 16% of the respondents (n = 5) considered improving genomic knowledge only somewhat important. In sum, the majority of the physicians felt improving their genomic knowledge was highly important but this activity was not urgent. This result was similar to the findings of the Burke et al. (2006) study of health professionals from family practice, neurology, cardiology, and dermatology agreed or strongly agreed (90%) with the statement, "genetics is increasingly important and must be given more attention in my training." (p. 112).

Since most physicians considered it important to improve their genomic knowledge, we asked whom they think should be responsible for updating them about genomics. Respondents could choose multiple answers for this question (i.e. "check all that apply"). Physicians viewed themselves to be most responsible for increasing genomic knowledge followed by medical training and research institutions. 84% of the physicians thought they themselves were responsible for updating their genomic knowledge (Table 3). 64.5% of the respondents felt that medical schools and Genome British Columbia (an arms length provincial government funder) should hold some responsibility for education. In other words, the physicians reckoned that Genome BC should spend more funding on research and projects that can enhance their genomic

knowledge and alleviate their genomic educational needs. Educating professionals and the public is a goal of Genome BC, so this would be a strategic opportunity to focus on. The results suggest there is a need for better strategies and guidelines for enhanced genomic education amongst physicians. Professional training, workshops, clinical rounds, continuing medical education (CME) accredited events are potential tools that can help physicians update their knowledge of genomic sciences and technologies.

**Table 3. Stakeholders responsible for updating medical oncologists about genomics**

<b>Stakeholders</b>	<b><i>f</i></b>	<b>Percent of Cases (%)</b>
Oncologists should update themselves	26	84
Medical Schools	20	64.5
Genome BC	20	64.5
Genome Sciences Centre	18	60
Regional Health Authority	8	26.7
Ministry of Health Services	5	16.7

As the participants considered it important to improve their genomic literacy, this research identified potential strategies for clinician genomic education through our systematic review including professional training and workshops or tutorials. One of the important themes in the development of genomic education is to identify the knowledge gaps among physicians. Researchers designed questionnaires or interviews with medical practitioners to determine which aspects of genomics they would like to receive more

education or training in. After identifying the knowledge gaps, the researchers designed or set up professional workshops or training to perform educational intervention for physicians. Before and after genomic literacy training, physicians typically receive questionnaires in order to examine the difference or increase in their genomics knowledge and evaluate the impact of the training. Some of the professional training programs or workshops were developed by experts and institutions in genomics science such as the American Academy of Family physicians (Clyman et al., 2007), Genetics Education Unit at the Murdoch Children's Research Institute (Metcalf et al., 2005), City of Hope Comprehensive Cancer Center (Blazer et al., 2002, 2004, 2005, 2011), and The Dutch College of General Practitioners (Houwink et al., 2014). Most of these studies were conducted after the completion of the HGP in 2003 when genomics became a popular topic of interest in the scientific and biomedical fields. Based on these two approaches, researchers can assess the gap in genomics literacy amongst their target population and test the effectiveness of their training methods.

The systematic review also identified two studies that discuss strategies to effectively integrate pharmacogenomics or personalized medicine into medical education and practice. Nickola et al. (2012) suggested that professional education curricula should incorporate pharmacogenomics competency in pharmacology, drug selection, drug dosage, and drug to drug interactions for health professionals, more particularly pharmacists, to better understand and apply personalized medicine in clinical practice. The authors recommended The George Washington University's (DC, USA) undergraduate degree program in pharmacogenomics and Shenandoah University's School of Pharmacy (VA, USA) as templates for pharmacogenomics training content.

The other study targets computational systems, more particularly electronic health records (EHR), to provide clinicians with up-to-date actionable information for pharmacogenetics test results (Bell et al., 2014). This active clinical decision support tool delivered through a computational system can optimize clinical utility and effectiveness of pharmacogenomics, and ultimately may improve patient care and outcomes.

Two studies applied online methods such as online modules or websites to provide materials and learning tools to assist physicians in updating their genomic knowledge (Houwink et al., 2014; Wilcox et al., 2013). For example, Houwink et al. (2014) combined a professional training model called Genetics e-learning Continuing Professional Development (CPD) module on 600 Dutch general practitioners, with a randomized controlled trial on 80 of them to measure the outcomes of the training. The result showed that the CPD module was a “feasible, satisfactory and clinically applicable method to improve oncogenetics knowledge” (p. 310). The educational effects of this module may inform the development of other online genetics modules for physicians, which could have an impact on a global scale. In addition, a study conducted by Wilcox et al. (2013) measured the use of GeneInsight Clinic (GIC), a web-based tool designed to improve clinician access to up-to-date genetic results. The study found that “GIC greatly increased the likelihood that a provider would receive updated variant information as well as reduced the time associated with distributing that variant information, thus providing a more efficient process for incorporating new genetic knowledge into clinical care” (p.e117). As a result, incorporating health information technology systems and other online tools as a platform for genetics and genomics education is innovative and effective

educational resources for physicians, which results in better utilization genetic information in clinical practices.

In addition, sociocultural elements also need to be taken into account. Genomic literacy involves not only scientific and clinical values, but also social and cultural values. Ethnicity, language, and religion affect how any given culture will interpret genomic knowledge. Saleh et al (2009) conducted a study with 53 clinical genetics practitioners, and found it challenging to overcome the cultural stereotypes when dealing with culturally diverse patients. As a result, cultural competence should also be included in professional genomics training for physicians.

Overall, genomics training, workshops, or tutorials can all be useful to improve physicians' genomics literacy. Medical schools in the US and Canada are also carrying out several innovative teaching strategies to incorporate genomic knowledge into their curricular time: "Flipped classroom exercises, where basic content is delivered outside of class and applied during active, in-class exercises, and online learning account for smaller but significant portions of teaching time" (Plunkett-Rondeau et al., 2015, p. 931). They also update their curricula with specific sets of genomic topics most pertinent to current state of medical genomics in accordance to the Association of Professors of Human and Medical Genetics Core Curriculum guideline (Hyland et al., 2013) including "personalized medicine, direct-to-consumer genetic testing, genome-wide association studies, pharmacogenetics, and bioinformatics" (p. 932). It is important for medical schools to keep their curricula topics updated in relevance with the rapid advancement of medical genomics.

## Pedagogical role of POG through multidisciplinary collaboration

In addition to professional training and point-of-care practice tools, enrolling in a genomic clinical trial is also a good way to improve genomic literacy. The survey asked the participants to select their goals in partnering with POG. 39% of respondents (n=12) collaborated with POG to find effective treatment for their patients (Table 4). An interesting and unexpected finding was that 35.5% of our respondents (n=11) view POG as a site to find effective treatment *and* learn more about genomics. Most notably, there are two respondents who collaborate with POG just to learn more about genomic research. As a result, apart from being a clinical trial for finding effective treatment, POG also plays a pedagogical value of educating genomics to the oncologists.

**Table 4. Goals in partnering with POG**

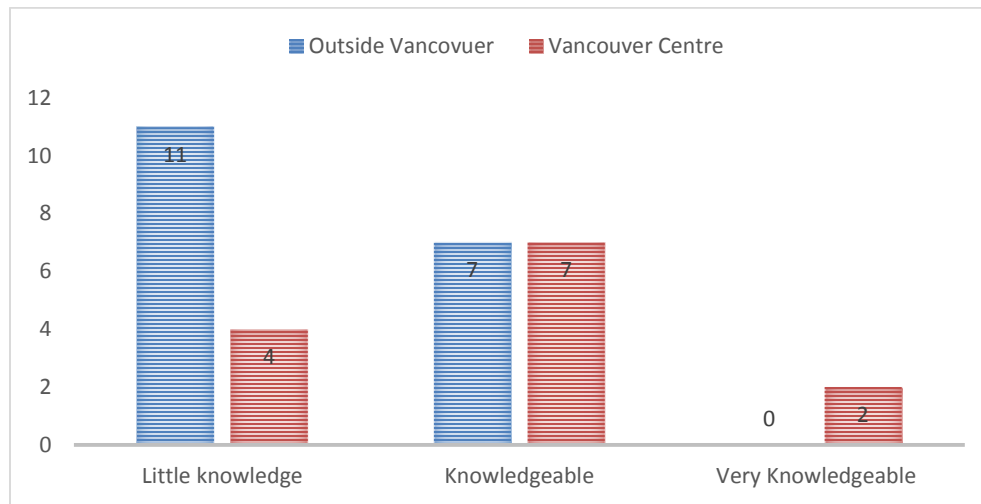
Goals in partnering with POG	<i>f</i>	Percentage (%)
Find effective treatment	12	38.7
Find effective treatment Learn more about genomics	11	35.5
Find effective treatment Get access to certain drug Learn more about genomic research	6	19.3
Learn more about genomic research	2	6.5

Not only is POG an educational site for physicians about genomics, it also helps elucidate the communication or discussion between physicians and patients regarding genomics:



educational for me (individual cases as well as genomic landscape of cancers; especially breast cancers since I treat these). it is useful to understand/be part of a process that pts will ask about increasingly over time (will *help me navigate/demystify it*, put it into context for them) (POG012)

There is a tendency to think geography plays less of a role in learning in this global era of rapid information deployment on the Internet. However, the survey yielded a surprising finding geography plays an important role in variations in MOs genomic literacy. We also found geographic location plays a role in levels of genomic knowledge in BC. MOs who work in Vancouver reported a higher level of knowledge about genomics on average than those who work outside Vancouver (Fig. 5). More respondents who work outside Vancouver reported little knowledge about new genetics technologies compared to those who work in Vancouver (73.3% vs. 26.7%,  $P < 0.07$ , Fisher exact test). Likewise, no respondents who work outside of Vancouver reported being very knowledgeable or expert in whole genome sequencing compared with those work in Vancouver (0% vs. 30.8%,  $P < 0.09$ , Fisher exact test). The data showed the domain experts who reported the highest levels of knowledge about genomic technologies are located in Vancouver. Those located outside greater Vancouver, the major urban center in BC, reported lower levels of genomic knowledge on average.



**Figure 5. Level of knowledge in relations to Location**

Respondents who work outside Vancouver reported lower levels of genomic knowledge than those who work in the metropolitan center. Vancouver is the central hub and a milieu of innovation for professional and educational networks connecting different medical stakeholders with medical skills and expertise. POG represents spaces of convergence for oncologists, pathologists, bioinformaticians, bioethicists, and health economists. Proximity to a metropolitan center like Vancouver, Boston, or New York can have an impact on the level of genomic knowledge possibly due to easier access to genomic training, workshops, or conferences and other face-to-face community opportunities. As a result, it is going to be important to take into account geographic location to identify the best strategies and targets to address the educational needs. To design better genomic training pipelines, genomic scientists and policy makers should target doctors who work outside major cities and metropolitan centers. The POG team has started creating targeted educational strategies for those working in regional areas of the province. Also, they are creating ‘POG-casts,’ which are short form educational videos for YouTube. Clinical genomics trial programs such as POG have a significant

pedagogical role for working doctors and physicians to learn more about genomic through utilizing the technologies and collaborating with other medical stakeholders.

## **POG as “hope technologies”**

POG plays a significant pedagogical role in genomic education mainly because it represents *spaces of converges* or the meeting of the minds between different medical stakeholders. When asked to describe the most valuable aspect of POG, many of the oncologists recalled the opportunities to learn, collaborate, and interact with different medical teams regarding genomic sequencing and genomic information interpretation. Some oncologists described POG as a new origin of hope for cancer patients or the future of oncology:

I have not had the opportunity yet to benefit from the process but hope to learn more about my patient's cancer and the process in the next several weeks. I find POG valuable primarily as an exciting research development, and a collaboration between scientists and clinicians as well as informaticians. It *gives me hope* we may discover useful information in future and it *gives patients hope* that research truly is producing advances for some people (...) If an actual useful treatment recommendation comes for a patient of mine, this will feel like a lottery win, as I don't have high expectations for the majority of people, that we will identify a particular therapy that will make a large difference. In effect, I feel the gains will be incremental, but we have to start somewhere. (POG001)

This is a work in progress where patient benefit is *possible but very unlikely*. It is being rolled out in the media as "*reading the genetic blueprint of the cancer*". This is research. Hopefully, it will *evolve into something worthwhile* in the future. (POG022)

Sociologists have found that in the network age of information society, geography still greatly matters. The central hubs of innovation can attract capital, experts, and

infrastructures for the development and diffusion of technologies. POG represents the synergy and innovative milieu (Castells & Hall, 2014) for genomic research in terms of network connecting multidisciplinary medical stakeholders with different styles of reasoning and practices within a clinical trial system that encourages the free flow of information, and the exchange of knowledge and skillsets, contributing to the technological diffusion of genomic sequencing technologies into clinical practices. As such, POG plays a significant role as an innovative milieu where the synergy operates effectively to generate both innovation and knowledge through human interaction within the social organization and institutional support. As a result, the significance of POG expands beyond clinical production and application of genomic information, and takes over the pedagogical role of producing and disseminating genomic knowledge to other medical professions collaborating with POG. Taken together, despite the dominance of the Internet, or the emergent of big data and information communication technologies, geographical location, or territorial structure has a significant impact on the production and application of genomic innovation and knowledge.

Representing innovative milieu and spaces of convergence, POG carries a sense of hope for the biomedical innovations of genomics. Contemporary genomic technologies operate within the field of hope as Sarah Franklin called it “hope technologies” (Franklin, 1997; Rose, 2007). At the time of the survey, the oncologist (POG001) did not benefit directly from using genomic sequencing. Yet, s/he was very optimistic about POG, as it instills and maintains the hopes of both the oncologist and the patient for an effective cancer treatment. Hope postulates an imagined but achievable future that will defeat the patient’s illness and suffering and advance clinical innovation of genomic technologies.

The hope connection between patient-physician relationships also corresponds to the “political economy of hope” in which hope is the key element to sustain the funding of clinical genomics cancer research and institutions like POG (Brown, 1998; Novas, 2006). The political economy of hope manifest genomics as human “blueprint” or “master code” embedded in both scientific and media communication as a way to define our personal identity, to triumph all diseases and sufferings, and to predict our future fate, on the basis of our genome structures.

This concept of “hope technologies” resonates with the idea of Sheila Jasanoff about sociotechnical imaginaries as “collectively held, institutionally stabilized, and publicly performed visions of desirable futures, animated by shared understandings of forms of social life and social order attainable through, and supportive of, advances in science and technology” (Jasanoff, 2015, p. 6). Linking genomic technologies with sociotechnical imaginaries helps illuminate the relationship between collective formations with individual identity and social conduct. As a whole or a nation, we are striving for cures or treatments of cancer and other acute diseases. Genomic technologies provide us with the sociotechnical imaginary that it is possible. Genomic technologies, however, also individualize our vitality and transforms our selves into biological citizens. As biological citizens, we are constantly shaping our lives through acts of conduct and activities such as diet, lifestyle, plastic surgery, genetic testing, and drug regime, in order to enhance ourselves and manage the risks of disease (Rose, 2009). In the personalized world of biomedicine, experimental cancer clinical trials represent sociotechnical imaginaries to frame risks and benefits of the co-produced realities constituted by the

social orders of science, technology, and society, rendering biological social control on our genes, tissues, and modes of subjectification.

## **Conclusion**

The main limitation of this survey is the raw numbers of participants and reliance on some self-report item, namely the instruments for measuring levels of genomic literacy. The sample size limited the ability to apply more inferential analyses such as logistic regression models to identify more associations between our variables. Other studies have employed tests to measure genomic literacy. We considered this option but did not pursue it because of the other goals of the survey, and the limited time respondents would most likely spare to complete it. However, the survey captured almost 30% of all working MOs in BC in the survey population. This is a solid foundation to build on for future studies. The strengths of this study include the rigorous, multi-step process to construct and validate the questionnaire. This survey is a co-production between social scientists and medical domain experts. The survey adapted existing items and measures from other questionnaires examining genomic knowledge of physicians (UBC Physician Education, Middleton et al., 2016). The survey was also validated twice through a physician who is an expert in clinical genomics and a pilot test with a feedback mechanism. Another strength of our study is the consistency in our findings with other studies in the same research, which showed a low level of genomic knowledge and a mixed attitude regarding genomics. Some might argue that physicians who work at experimental clinical trials like POG would have higher genomic knowledge than other

physicians. However, majority of our respondents reported to have low genomic literacy. This implies that other physicians outside the BCCA network are likely to have even lower levels of awareness, knowledge, and favorable attitudes toward genomic technology.

Genomic technologies are on the horizon to be a part of oncology practice, but the adoption of genomic technologies faces many barriers including the lack of genomic literacy among physicians and a lack of genomic education in medical schools. The majority of the respondents reported that medical training systems do not sufficiently prepare future health professionals with enough genomic materials and education. Arguably, as scientific and medical discoveries are taking place rapidly, it is very difficult for rigorous systems at medical schools to keep up with all the new advancements. Medical training is one of the most established education systems in the world accumulating thousands of years of medical discoveries and experiences. Genomic sciences such as genome sequencing have only been around since 2003, and scientists are learning more about genomics than they ever did in history. Many uncertainties and drawbacks of genomic technologies are still waiting to be unveiled. As a result, the diffusion of genomic education into medical training systems is not a linear pathway, but a challenging and incremental process. We need collaboration between different stakeholders in genomic science and medicine to identify and develop effective pedagogical tools. Medical schools are a good start. However, we also need better avenues for doctors to apply their life-long learning skills to update genomic knowledge themselves via different self-learning tools and resources. Some studies suggested

identifying learning needs of physicians about genomics and organizing professional genomic training or workshops to improve their genomic knowledge. Studies also pointed to the Internet or online tools as asynchronous teaching and learning resources that would fit better and more productively with extremely busy schedules of physicians. More applied trainings and guidelines to improve physicians' genomic literacy will bolster the integration of genomics into primary care.

The lack of genomic literacy signifies how clinical genomics is generating a new style of practice in oncology. This new style of practice operates within spaces of convergence in big data clinical genomics comprising disparate entities of people and technology from the fields of medical science, molecular biology, and computer analytics. Therefore, genomic sequencing requires a multidisciplinary team of genome biologists, medical geneticists, and bioinformaticians to assist physicians in analyzing and interpreting the results. As a result, we might have been focusing on the wrong direction or even asking the wrong questions. Physicians need to improve their genomic literacy; however, the vital question is to what extent do they need to assimilate more knowledge about genomics? Or what are the best approaches to optimize the multidisciplinary cooperation between different medical social groups for the clinical decision making process of genomic information? These research questions indicate a potential field for future research to advance knowledge translation and technological diffusion of genomics into clinical care. These questions also lead us to the next chapter, exploring the co-production of knowledge, risks, and benefits of genomic information through communicative and discursive processes between different medical stakeholders in cancer clinical trials.



## Chapter 5.

# **Co-production of genomics through communication and discourse: experiences of oncologists with genomics**

## **Background**

Rapid developments in genomic science and biomedical innovation produce novel knowledge that can also generate diagnostic uncertainty (Timmermans et al., 2016).

Clinicians struggle with interpreting genomic data and applying it to clinical practices.

This (translation?) process has tremendous impacts on ontologies and practices surrounding disease, the identity of patients, and life strategies of patients like treatment decisions (Timmermans & Buchbinder, 2010). This is an early stage of adoption as genomics moves from scientist stakeholders to medical practitioners and the public. Put another way, genomics is moving from the research bench to the clinical bedside. It is critical to update our understanding of doctors' perspectives and experiences during the adoption process. This knowledge can be fed back to clinical trial researchers to help develop clinical genomic technologies. Understanding doctors' attitudes and experiences working with clinical genomics can help direct practical guidelines for medical students and practicing doctors.

In this chapter, I examine the critical discrepancies between promises of clinical genomics and the social implications of diagnostic results. The research will build my analytic frameworks from scholarly work on diagnostic uncertainty and bioclinical collectives in clinical genomics (Timmermans & Buchbinder, 2012; Cambrosio & Keating, 2011). Many researchers conduct studies on diagnostic uncertainty or genomic

diagnosis to understand the knowledge production of genomics, along with social impacts of uncertainties in genetic risks on patients (Skinner et al., 2016; Timmermans et al., 2010, 2016). I will carry on this tradition of research to explore the experiences of oncologists working with clinical genomics in experimental clinical trials setting at POG. In order to overcome the diagnostic uncertainty of genomics, the POG team is developing a classification system of biomarkers, matching them with the right treatment options. Representing the spaces of convergence, cancer clinical trials like POG illuminate how medical practitioners narrate and negotiate the risk and uncertainty of genomic information through the process of communicative and discursive formations. The intent of this line of research is to reveal the underlying risks and challenges of integrating clinical genomics into clinical care, while accounting for the social and political processes in the knowledge production of genomic data.

### **Attitudes of physicians towards genetics or genomics: a literature review**

Many studies have measured physician attitudes towards genomics to understand the perceived values of genomics in clinical practices. Some studies have shown that there is a positive correlation between attitudes of physicians towards genomic technologies and their willingness to adopt the technologies or to improve genomic knowledge (Gray et al., 2014; Martin & Currie & Finn, 2009). One of the reasons for this relatively low number may be that our search terms focus more on the knowledge and education of genomics, rather than the attitudes toward it. The items physicians are often asked about are: their willingness to incorporate genomics technologies into their

practices, the likelihood to refer genetic testing or counseling for their patients, the perceived importance of genomics in the healthcare system, and the value of genomics for treating cancer patients. Researchers tend to use survey, interview, and focus group methodologies to study this phenomenon. Measuring attitude or sentiment can be difficult for researchers to design measurable studies and for respondents to give comparable answers. One way to measure genomic attitude is to also assess genomic knowledge in order to infer about the relationship between the two. The attitude or willingness to adopt genomic technologies into clinical practices could also result from the level of genomic knowledge to analyze, evaluate, and apply genomic information. Gray et al. (2014) found physicians who decided not to adopt genetic testing in clinical practices or to not disclose test result, tend to have lower genomic confidence and lower reported baseline understanding. In other cases, the main factors that discourage physicians to incorporate genetic testing are uncertainties in the safety and effectiveness of preventive genetic tests (Mountcastle-Shah et al., 2000; Timmermans et al., 2016). The researchers reported that a majority of the interviewed physicians express that uncertainty as to the clinical utility (60%) and clinical validity (43%) of predictive genetic testing impeded them from adopting genetic tests in clinical care. Another barrier to incorporation of genomic technology into practice is a lack of government supported programs. Martin and colleagues (2009) conducted a qualitative research based on eleven case-study sites and focused on attempts by pilot programs funded by the initiative to embed knowledge and provision within primary care in England. The study addressed a lack of intrinsic interest in clinical genetics among primary care staff was “compounded by national targets that focused their attention elsewhere and by service structures that rendered genetics a

peripheral concern demanding minimal engagement. Established divisions between the commissioning of mainstream and specialist services, along with the pressures of shorter-term targets, impeded ongoing funding” (Martin et al., 2009, p. 204). From this study, we learned that government funding and support play a vital role in the development of genomic education and the diffusion of genomic technologies into clinical settings.

Other studies showed a positive trend in attitudes towards genomics. For example, Acton et al. (2000) and Escher & Sappino (2000) showed that most physicians had favorable attitudes toward genetic testing and reckoned that genetic information provides useful information in cancer diagnosis and treatment. Fry et al. (1999) also supported this finding in their study by showing that over 80% of their respondents agreed or strongly agreed with the value of genetic screening or genetic counselling toward cancer patients. Similar findings in a study conducted by Burke et al. (2006) with a series of surveys, interviews, and focus groups with 143 family practitioners and found 90% of their participants agreed or strongly agreed with the statement, “genetics is increasingly important and must be given more attention in my training.” A large majority (92%) disagreed or strongly disagreed with the statement, “learning about genetics is not a productive use of my time” (p. 112). Overall, physicians expressed a positive attitude toward increasing their genomic knowledge, and a desire to adopt genomics into their practices. In the *diffusion of innovations* theory, Rogers (2010) maintains that positive or negative attitudes can promote or thwart the adoption of new technologies. For example, Gray and colleagues (2014) found that the attitudes of physicians towards genomics could influence their applications of multiplex tumor genomic testing into practice.

Therefore, this area of research on the attitudes of physicians towards genomics is important in understanding the adoption of genomics into clinical care.

## **Oncologists' attitudes towards genomic technologies**

This section of the survey asked the respondents to predict the impact of genomic technologies on their practice in the near future. The respondents rated 7 items on a scale from 1 = "no impact", 2 = "minor impact", 3 = "major impact". We found (Table 5) 67.7% of the respondents predict that in the next years genomic technologies will have major impact on drug discovery (mean = 2.68; SD= 0.48). Genomic technologies will also have major impact on helping oncologists select course of treatment (58%) (mean= 2.55; SD= 0.57) and sequence whole genomes for their cancer patients (58%) (mean= 2.48; SD= 0.68). However, the majority of our respondents think genomic technologies will only have a minor impact (58%) or no impact (9.7%) on making a diagnosis (mean= 2.23; SD= 0.62). More than half of our respondents (61.3%) think genomic technologies will have a minor impact on extending and improving lives (mean= 2.19; SD= 0.6). Overall, the majority of MOs envision that genomics science and technologies will have some impact on their oncology practices but nothing as major or significant (mean = 2.19-2.68; Item main effect  $F(6,180)= 5.1, P < 0.0001$ ).

**Table 5. Impact of genomics on oncology practices in the next 5 years**

<b>Impact</b>	<b>No impact (%)</b>	<b>Minor impact (%)</b>	<b>Major impact (%)</b>	<b>Mean (SD)</b>
Making a diagnosis	9.7	58	32.3	2.23 (0.62)
Drug discovery	0	32.3	67.7	2.68 (0.48)
Repurposing existing drugs	0	48.4	51.6	2.52 (0.51)
Selecting course of treatment	3.2	38.7	58.1	2.55 (0.57)
Sequencing transcriptomes	6.5	54.8	38.7	2.32 (0.6)
Sequencing whole genomes	9.7	32.3	58	2.48 (0.68)
Extending and improving lives	9.7	61.3	29	2.19 (0.6)

We also asked the respondents to express concerns they have about expanding genomics science and technology into their practices on a scale of 1 = "unconcerned", 2 = "somewhat unconcerned", 3 = "somewhat concerned", 4 = "very concerned." The three most concerning issues our respondents have when applying genomics science and technologies into their clinical practices are: cost (61.3%) (mean= 3.58; SD= 0.56), patient comprehension of genomic science and technologies (48.3%) (mean = 3.39; SD= 0.67), and clinical usefulness of genetic data (42%) (mean= 3.26; SD= 0.78; Table 6). Overall, participants are mostly just somewhat concerned about pitfalls genomics science and technologies might bring about (mean = 2.55 – 3.58, Item main effect  $F(7,210)=8.03$ ,  $P<0.0001$ ).

**Table 6. Concerns about genomics science and technology**

Concerns	Unconcerned (%)	Somewhat unconcerned (%)	Somewhat concerned (%)	Very concerned (%)	Mean (SD)
Clinical usefulness of genetic data (specificity/sensitivity/reliability)	3.2	9.7	45.2	41.9	3.26 (0.78)
Extra effort without changing treatment	0	12.9	48.4	38.7	3.26 (0.68)
Decision making on what results to return to patients	3.2	13	54.8	29	3.1 (0.75)
Results leading to ineffective or harmful treatment	3.2	22.6	42	32.2	3.03 (0.84)
Cost	0	3.2	35.5	61.3	3.58 (0.56)
Immaturity of genomic science and technologies	3.2	19.3	42	35.5	3.1 (0.83)
Patient comprehension of genomic science and technologies	0	9.7	42	48.3	3.39 (0.67)
Unexpected germline findings	6.4	42	42	9.6	2.55 (0.77)

## Oncologists' experiences and perceived values of POG

This part of the survey explored the expectations, experiences, and values of POG amongst medical oncologists. We asked the oncologists to rate on a scale from 1 = "strongly disagree", 2 = "somewhat disagree", 3 = "somewhat agree", 4 = "strongly agree" on 9 items in order to evaluate their experiences with POG. Even though there are only 29% of the respondents that are satisfied with their POG experience (mean= 3, SD = 0.72) and only 25.8% strongly agree that POG is valuable to their experience (mean =

2.94, SD = 0.89), the majority of the respondents (61.3%) want to collaborate with POG again (mean = 3.52, SD = 0.72). Overall, oncologists are positive about their experiences with POG (mean = 2.52 – 3.52, Item main effect  $F(6.5,196.7)=11.8$ ,  $P<0.0001$ ; Table 7)

**Table 7. MOs’ experiences and perceived values with POG**

<b>Statements</b>	<b>Strongly disagree (%)</b>	<b>Somewhat disagree (%)</b>	<b>Somewhat agree (%)</b>	<b>Strongly agree (%)</b>	<b>Mean (SD)</b>
I feel more confident making treatment decisions after becoming informed about my patients' genome	12.9	29	51.6	6.5	2.52 (0.81)
I had enough information and knowledge to understand the POG meeting and results	6.5	38.7	41.9	12.9	2.61 (0.8)
I feel confident that I could communicate POG results to my patients	9.7	22.6	61.3	6.5	2.65 (0.75)
POG added another layer of confirmation to existing indicators	12.9	29	51.6	6.5	2.52 (0.81)
I now want to apply tumour sequencing more often in my practice	9.7	35.5	38.7	16.1	2.61 (0.88)
Meeting with the POG team was worthwhile	3.2	3.2	61.3	32.3	3.23 (0.67)



I'm satisfied with my POG experiences	9.7	9.7	51.6	29	3 (0.89)
I will collaborate with POG again	3.2	3.2	32.3	61.3	3.52 (0.72)
Overall, POG is valuable to my practice	9.7	12.9	51.6	25.8	2.94 (0.89)

Furthermore, to examine the practical values of POG, the survey also examined whether the participants ever changed any of their patients' management plans based on the clinical results they received from POG. While 39% of oncologists (n=12) changed their patient's management plans based on POG clinical trial results, the majority of our sample (61%) did not change patient's management plans. In fact, this survey data matches with the actual clinical records from POG. So far, POG has had 219 sequencing cases, only 166 of which are clinically actionable, and only 78 cases (35.6%) have taken actions in changing patient's management plan based on POG sequencing results. The actual data from POG on MOs changing their patients' management plans (35.6%) matches with the result on the same topic from our survey (39%). Therefore, our survey data has a statistically significant implication reflecting the uncertainties of genomic technologies despite their hype and promises of treating diseases and improving lives.

The next finding in the survey reflects the reasons that oncologists were reluctant to change their management plans based on POG results. The participants were asked to share the concerns they had when recommending treatments suggested by POG. Since it was a multiple answer question, the similar answers were grouped together including all the responses regarding the issues with the drug. The data shows that the main concern

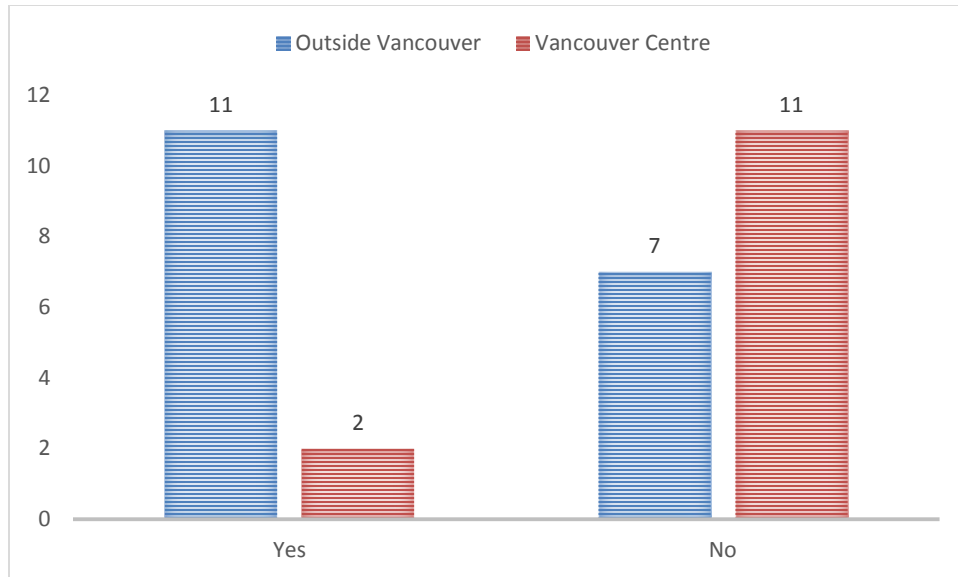
oncologists had were that either drug suggested by POG was not approved for use or off label or underdeveloped or not accessible or too expensive (Table 8). Another reason that POG failed to help MOs change any of their patient’s management plans is that POG did not recommend any drug to any of their patients. These results indicate that political and economic factors of the pharmaceutical industry strongly impact the development and applications of genomic science and technologies into clinical practice.

**Table 8. MOs concerns towards POG clinical results**

<b>Concerns</b>	<b>N</b>	<b>Percent of cases (%)</b>
Drug not approved for use or off label	14	45.2
Drug underdeveloped or not accessible	13	42
POG did not recommend a drug for any of my patients	12	38.7
Drug too expensive	9	29
Other	8	25.8
None - I recommended the treatment options to patients	5	16
I did not agree with the recommendation	5	16
The patient was not comfortable with the recommendation	0	0

Lastly, the survey asked respondents whether the provincial government should publicly fund POG. While 58% of our respondents (n= 18) oppose government funding for POG, 42% (n=13) think POG should be publicly funded. To clarify the oncologist's opinion on POG funding, we designed a follow-up question asking the respondents to clarify why they think POG should or shouldn't be publicly funded by the provincial

government. The results reveal two trajectories of thoughts in their support for the POG funding: technology optimist/determinist or liberal (Table 9).



**Figure 6. POG funding**

A technology optimist/determinist tends to think genomic science and technologies will be the future of our healthcare that will advance our standardized of care and need to be subsidized by the government. A liberal believes that government has the responsibility to fund clinical research projects and initiatives such as POG. The other group of oncologists who oppose to POG funding tends to be more skeptical about the clinical utility and validity of POG. They think POG is still just an experiment and a clinical trial with no real clinical impact. Lastly, we identified some meaningful associations between MOs' location and their number of cancer patient with their opinion on POG funding. More respondents who locate outside Vancouver tend to think POG should be funded compared with those locate in Vancouver Centre (84.6% vs. 15.4%,  $P < 0.03$ , Fisher exact test, Fig. 6). In addition, MOs who have more cancer patients per year

also tend to support POG public funding compared with those who have fewer cancer patients per year (69.2% vs. 30.8%,  $P < 0.02$ , Fisher exact test).

**Table 9. Reasons for POG should or should not receive public funding**

<b>Themes</b>	<b>Respondents</b>	<b>Illustrative excerpt</b>
Technology	POG 003	"Important aspect of best clinical management"
optimist/determinist	POG 007	" It is an important technology and is likely the future of oncology (though initial basket studies seem disappointing) and clearly there is a lot of work to be done in this area."
	POG 021	"Such that everyone can receive personalized cancer treatment"
Liberal view about the role of government on welfare, especially healthcare systems	POG 019	" The government has an important role in promotion of research."
	POG 001	" I feel the government should, in general, fund research more routinely and generously. I don't feel they should necessarily entirely fund POG, but should fund our cancer system so that clinical research is better funded, in particular."
	POG 020	" I think POG should be funded at least in part of the provincial government because it stands to

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		potentially improve our ability to give useful therapies and not give useless therapies"
Skeptical about the clinical utility and validity of POG	POG 011	"still experimental, cumbersome, time consuming process. no clear improved outcomes (whether PFS, QOL, or OS) related to pts participating in POG - this is usually the benchmark for public funding."
	POG 015	" It does not change management yet. I don't see value in universal testing for all patients. It needs to be a clinical trial a bit longer before public funding."

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## **An inquiry into clinical utility of POG**

Many oncologists are skeptical about the clinical utility and validity of genomic information. Analyzing and interpreting genomic sequencing data is the task of bioinformaticians and genome scientists. For every case, clinicians at POG receive a report from bioinformaticians of possible mutation pathways that could potentially help clinicians choose effective drugs or other therapeutics treatment to target the mutations. However, clinicians do not have enough genomic knowledge to interpret or make sense of the mutation pathways, and hence, it creates some uncertainties about the genomic results. Many participants in our survey expressed the frustration regarding genomic data:

the results are *clinically meaningless* in the vast majority of time the study is useful for "discovery" but not clinical practice (POG006)

Don't talk about treatments if you don't know what the genomics mean. Talk about tumor subtypes. (POG006)

The approach taken with POG goes against our fundamental principle of knowing the chance for benefit/harm for treatments that are proposed. A somewhat casual conversation is had at the end of the POG review about what could be tried for a patient based on the sequencing that was done, but often there is no evidence that a suggested treatment may actually benefit the patient (...) Without being able to deliver suggested treatments and follow patients to see how they actually do I am not sure what we are accomplishing except for demonstrating that the tumors can be sequenced. There is concern that patients are going into this project with *unrealistic expectations* and we are not studying/learning from what POG may suggest to do in terms of treatment...(POG024)

As genomics is still in the early stage of adoption and development, the clinical utility of genomic technologies is still questionable. Some of the respondents heavily criticized the diagnostic uncertainty of genomic data by asserting it “clinical meaningless” and giving their patients “unrealistic expectations”. In the political economy of hope, genomic technologies also face many critiques regarding the clinical utility of its data. While some are hopeful about an onco-genomics future, many are skeptical about the usefulness of the data as there is no evidence that the treatment will be effective. In laboratory research, it is more tolerable to make mistakes and learn from your mistakes. Many important scientific discoveries happen by mistakes or accident. Nevertheless, in clinical settings, oncologists are not allowed to make any mistakes, as the cost of it is a human life. As scientists and clinicians are learning more and more about genomics every day, there are no systematic sets of protocol that can be applied for

genomic mutations. Genome sequencing can produce a lot of information beyond what a clinician needs and understands. There are a lot of noises in the data that needs to be filtered out. Consequently, clinicians are also struggling to figure out what is the right data or information to take into consideration of clinical treatment. At times, clinicians have to rely on bioinformaticians to filter and interpret the data for them. Bioinformatics is an interdisciplinary study that combines computer science, biology, statistics, mathematics, and engineering to analyze and interpret biological data. A bioinformatician does not have official education or trainings in medicine and health sciences. Therefore, there is a conflict or lack of equivalence between how a bioinformatician interprets the data versus how a clinician understands the data. A bioinformatician may find a useful genomic pathway for a particular tumour. However, it does not guarantee that a clinician can translate and apply it into clinical practices. That generates the *genohype* or “unrealistic expectations” for genomics.

Genohype is a phenomenon in which genetics or genomics instills inaccurate and unrealistic hopes or expectations about human health (Struve, 2015). The rapid advancement in genomic science and research is generating a surfeit of previously unavailable genomic knowledge and information that inevitably create a diagnostic uncertainty about the clinical validity, reliability, and usefulness of genomics (Timmermans et al., 2016). This logic highly resonates with genetic tests producing low clinical validity with no effective treatment, which in turn would raise uncertainties and confusion among physicians and patients (Gray et al., 2014; McGowan et al., 2014). Therefore, when investigating the diffusion of genomic knowledge in healthcare systems,

it will be more effective if researchers also examine strategies to assess and evaluate diagnostic uncertainty engendered by genomic tests.

## **Diagnostic Uncertainty in Genomic Big Data**

Biomedical uncertainty has significant impacts on the life decisions of patients, the nature of disease, and the identity of patients. Reflecting from the observation notes from the POG meetings, many oncologists expressed their uncertainties about the clinical utility of genomic data. The survey data also shows the similar uncertainty trend when 61% of our respondents did not change their treatment plans based on the recommended genomic data results. This brings about uncertainties in patient-physician visits as physicians “didn’t know a lot” about genomics or that their “knowledge with regard to this whole area [about genomics] is really poor” (Christensen et al., 2015, p3). The failure to interpret the genomic testing results to patients can result in some significant new life changes. For example, an interview study revealed that the majority of women who carried the fragile X gene decided not to have a biological child as they did not want to pass on their pathogenic gene to their offspring (Rapsberry & Skinner, 2011). Another study shows that of more than 8,000 patients, about 2500 ended up having a procedure to remove their breast. However, the study found that in 49 percent of such cases, the mastectomy was either needless or was being carried out because of a failed previous operation (Donnelly, 2014). In the case of newborn screening, test results can produce false positive or conditions of uncertain significance. Newborns with testing results outside the standardized classification of conditions are referred as patients-in-waiting,



who “inhabit a liminal state between normalcy and pathology, imposed by medical screening and testing technologies aimed at secondary prevention, characterized by a lengthy process of medical surveillance to resolve diagnosis uncertainty, which may spill over into personal identity and other areas of life” (Timmermans & Buchbinder, 2010, p. 419). Therefore, this suggests biomedical uncertainty in WGS renders our selves as “somatic individuals” whose vitality and individuality are socially, not medically, defined, evaluated, and acted upon (Novas & Rose, 2000).

Genomic technologies also face criticism from clinicians concerning with the clinical utility of its data. While some are hopeful about an onco-genomics future, many are skeptical about the usefulness of the data as there is no evidence that the treatment will be effective. In laboratory research, it is more tolerable to make mistakes and learn from a researcher’s mistakes. Many important scientific discoveries happen by mistakes or accident. Nevertheless, in clinical settings, a mistake by an oncologist may cost a human life. As scientists and clinicians are learning about genomics, there are no systematic sets of protocol that can be applied for genomic mutations. Genome sequencing can produce a lot of information beyond what a clinician needs and understands. There is a lot of noise in the data that needs to be filtered out. Consequently, clinicians are also struggling to figure out what is the right data or information to take into consideration of clinical treatment. Many oncologists are skeptical about the clinical utility and validity of genomic information. Analyzing and interpreting genomic sequencing data is the task of bioinformaticians. For every case, clinicians at POG receive a report from bioinformaticians of possible mutation pathways that could potentially help clinicians choose effective drugs or other therapeutic treatment to target

the mutations. However, clinicians do not have enough genomic literacy to interpret or make sense of the mutation pathways, and hence, it creates some uncertainties about the genomic results.

## **Narrating uncertainty: Classification of genomic biomarkers**

Genomic sequencing technologies can produce up to 20,000 variants and many of which have uncertain significance. Scientists call these variants of uncertain significance (VUS). POG constitutes “bioclinical collectives” of clinical genetic experts, bioinformaticians, and laboratory experts, who undertake the task of interpret and negotiate the meaning of these VUS in order to address clinical uncertainty of genomic data (Timmermans & Tietbohl & Skaperdas, 2016). It is both a clinical and ethical battle to whether one should include a VUS in the genomic results report. The nature of a VUS is liminal and temporal, which there is no current supporting evidence to classify the molecular change as either detrimental or neutral. However, that does not mean a VUS is clinically useless, because over time there might be sufficient evidence to reclassify the VUS as benign or pathogenic. The current genomic information systems do not have a standardized and clinically-proven set of classifications for each gene or biomarker to match with an effective targeted drug or treatment. Biomarkers refer to medical signs or indicators of “normal biological processes, pathological processes, or pharmacologic responses to a therapeutic intervention” (Strimbu & Tavel, 2011). In other words, biomarkers can indicate healthy or pathogenic genes and their responses to drugs. One of the main objectives of POG is to expand the classification list matching each biomarker

with effective drugs or treatments. In order to do so, all genomic sequencing data at POG feed back to their classification systems of variants, in the hopes that they can reclassify all the VUS:

“Before, [bioinformaticians] gave us every possible [genomic] pathway and we were like “ohhhh we can’t read that so that doesn’t make sense”. Now as we have more experience, the outcome and some of our decisions go back to the system also helps us figure out what pathways we really should be looking at. So now the really nice thing about POG is that the information feed back on themselves. Arguably, POG is an individualized clinical trial, but to make it more powerful, it is that information feed back into the classification system, that the individualized results can affect changes on other people’s decision making. Because if it doesn’t work out on the patient, maybe it’s something we should have done and now we know better for someone else if that makes sense.” (POG oncologist)

This classification feedback system in cancer clinical trials like POG signals a collective turn in medical research via large-scale networks of clinical researchers and patients that generates a new style of oncology practice, blurs the distinction between research laboratories and clinical settings, and redefine social relations between medical stakeholders and between medical stakeholders and patients (Keating and Cambrosio, 2011). The meaning-making of genomic data and the classification system also postulate a complex decision-making process through communication and discourse between multidisciplinary medical stakeholders. The classification systems encodes an inextricable network of human actions, politics, arguments, agreements, agendas, values, and social relations of different actors involving in the process of meaning-making of genomic data (Bowker & Star, 1999; Chow-White & Green, 2013). Medical practitioners have their own style of reasoning and practice, or epistemic culture, toward how medical knowledge is produced (Cetina, 2009). As being a part of the spaces of convergence,

their epistemic cultures are situated within a social positionality or shifting networks of relationships with other social structures. Therefore, through the lens of their practices, communication processes, situated epistemic cultures, and social positionality, medical practitioners in clinical genomics trials come together in these social constellations as a bioclinical collective to co-produce knowledge and social order of genomic diagnosis.

### **Conclusion: Disruption and hope in genomic technologies**

The MOs in this sample showed a mix of attitudes toward the use of genomic technologies in clinical practices. The findings on the impact of genomics on oncology practices (Table 5) and concerns about genomic science and technology (Table 6) indicate that genomic technologies could change the way MOs understand the molecular causes of diseases by genome sequencing and personalize drugs and treatments particularly to a patient's genome. However, the uncertainties of clinical utility and validity of genomic information are a hurdle for MOs to incorporate genomic data into their diagnosis and treatments. The reluctance to adopt genomic technologies into clinical practices could also result from the lack of genomic knowledge to analyze, evaluate, and apply genomic information. These findings were consistent with the results from Gray et al. (2014) study, in which physicians, who decided not to adopt genetic testing in clinical practices or to not disclose test results, tend to have “lower genomic confidence and lower reported baseline understanding” (p.1320). As a result, the lack of genomic literacy could engender a negative attitude among physicians about the effect of genomic technologies in diagnosis and treatment and impede the adoption of genomic

technologies into healthcare systems. If doctors are not on board then it will be difficult to implement *and* develop clinical genomic technologies at the population level. On the basis of the educational deficiencies identified in this survey, the POG team has initiated applied cancer genomics symposiums for the physicians of BC to address some of these educational gaps.

Another barrier to the provision of genomics into clinical care is its diagnostic uncertainty. The rapid advancement in biomedical innovation takes place almost daily, which in turn generates novel medical knowledge and applications. This inflicts uncertainty among physicians on what and how to use genomic technologies and analyze the data. Some physicians prefer to stay in their comfort zone of medical knowledge and opt-out the use of genomic data for their clinical decisions. Some physicians even argue that genomic medicine goes against the fundamental principle of evidence-based medicine, as genomic data is full of uncertainty that does not guarantee the benefits or consequences of the treatment. With evidence-based medicine, the effectiveness and risks of the drugs has been tested and evaluated under clinical trials, and therefore, it offers a clinically-proven protocol of treatments. With genomic medicine, as it is designed to target individual genome structures of tumors, its effectiveness and risks vary considerably. Cancer clinical trials like POG are set up to overcome this diagnostic uncertainty in genomic medicine. POG are building a classification system for each biomarker to match with an effective targeted drug or treatment. As this process evolves over time, POG feeds back information into the system and generate evidence and protocols for treatments based on genomic medicine. The visions for genomics medical big data feedback mechanisms to produce long-term cancer treatments classification

represent a sense of hope and technological imaginary of POG discussed in the previous chapter. This sense of hope overweighs the uncertainties and disruption of medical knowledge engendered by genomic technologies. As genomic medical big data continues to expand in the hopes of improving health care for society, genomic literacy plays a key role in understanding the adoption of genomic technologies into clinical care. Genomic literacy can also help elucidate the health communication of risks and implications of genomic results between different medical specialists or between clinicians and patients.

## Chapter 6.

### Conclusion

That is, I learned that I was a cyborg, in cultural-natural fact. Like other beings that both scientists and laypeople were coming to know, I too, in the fabric of my flesh and soul, was a hybrid of information-based organic and machinic systems.

Haraway, 2004, 204

The goals of this thesis are two-fold. First, the thesis addresses the technological diffusion of genomics into oncology practice by examining the genomic literacy of medical oncologists in a clinical trial setting. The second goal is to draw attention to emerging trends in the relationship between science, technology, and human vitality. What is human vitality becoming in the genomics era? What forms of self, identity, body, and mind are in the making of genomic sequencing technologies? Foucault ruminates on life as being in the state of subjugation to power and knowledge. Living beings are placed under the political realm of the knowledge-power domination in which “knowledge is not made for understanding; it is made for cutting” and enslavement of the human body (Foucault, 1977, p. 88). In the nineteenth century, the body was under the clinical gaze of medical jurisdiction of doctors that extended beyond illness and diseases, to the maintenance of social order and control through the management of diseases, reproduction, and health risks. The rise of genomics leads us to the molecular gaze, in which our body is subjected to numerical and informational codes of “dividual” materials (Rose, 2007). Genomic sequencing technologies break down our biological structures

into sets of codes and data that can be stored, manipulated, reengineered, and commoditized. These biomedical innovations of genomics are made possible by the emerging digital cultural and information technologies, signifying the convergence of genomics and informatics for bioscientific constructions of human vitality. This gives rise to the spaces of convergence of genomics in cancer clinical trials where multidisciplinary medical stakeholders come together in these social constellations of biocollectives to co-produce knowledge and meaning with genomic information. In these spaces of convergence, different medical stakeholders have different styles of reasoning, practices, or epistemic cultures, in turn producing a contested space of medical expertise and beliefs. As such, this reflects the shift from clinical gaze to molecular gaze, in which the medical imperialism and therapeutic powers of doctors are challenged by a new style of practice involving other medical stakeholders in the clinical decision making. This thesis develops the concept of “genomic literacy” to explore this contested spaces of convergence between medical oncologists and data scientists involved in the knowledge production of genomics through the communicative and discursive processes that determine the success or failure of the technological diffusion of genomic technologies into clinical care.

## **Implications of genomic literacy on practitioners and clinical genomics**

To develop the concept of genomic literacy, I draw upon three areas of scholarship: health communication, information communication technologies (ICTs), and science and technology, in order to address the biomedical, informational, and



sociocultural natures of genomics. First, to understand the biomedical values of genomics, I conducted a survey to examine the level of genomic knowledge, education, attitudes, and experiences of MOs towards genomic applications in the cancer clinical trial. The findings show that there is a lack of genomic literacy and mixed attitudes towards genomics among MOs, which could potentially impede the transition of genomic technologies from bench to bedside. A recent report from the Secretary's Advisory Committee on Genetics, Health, and Society (SACGHS) also pointed out that a lack of basic genetic understanding among many health professionals could limit the adoption of genomic technologies into clinical practices (Teutsch, 2011). As such, clinical genomics is still in early stages of adoption where the clinical validity and utility still remain highly uncertain. There is a critical need to understand these early adopters, however.

Technology development of any kind can be better strengthened with domain expert input at the earliest stages. If not, then the risk is creating something that does not fit the user needs or their buy in. Therefore, the findings point to a high need for substantive applied genomics education for cancer physicians specifically right now. Medical schools, which are the front lines of medical education systems, will need to keep up-to-date with the rapid expansion of genomic science. However, medical schools are an old education model that are being strained and challenged by the novelty of clinical genomics. As genomics engenders a new style of practice, medical schools might not be capable of adapting to the new technologies and adopting well-suited pedagogy model to address them. Therefore, working doctors need opportunities to further their genomic education or training at conferences and workshops as well as point-of-care learning and practice resources.

The study yields some positive findings regarding the pedagogical role of POG. This thesis only managed to measure the genomic literacy of MOs who only account for one specific group of medical stakeholders at POG. However, MOs are the major medical stakeholder and the domain expert, who works on the front lines of adopting genomics into their medical diagnosis. They ultimately make the decision on whether or not they will use the insights of the data scientists and other medical stakeholders. In the survey, MOs reflected in the responses not only their experiences working with clinical genomics, but also working in the multidisciplinary collaboration environment of POG. Many of them deemed this multidisciplinary of POG as an opportunity to learn more about clinical genomics. Representing the spaces of convergence between multidisciplinary medical stakeholders, POG becomes not only a clinical site for experimenting clinical genomics, but also the meetings of the minds for social interactions, communication, and discussion to interpret, narrate, and produce knowledge and meanings of genomic data. With this finding about the pedagogical significance of POG, other cancer clinical trials could adopt this multidisciplinary approach of POG in order to provide both an experimental and education site for clinical genomics. Therefore, the biomedical importance of POG lies within the translational multidisciplinary or the spaces of convergence that creates a pedagogical site for practitioners to learn more about genomics. This is a novel finding from the survey, indicating a space of convergence is also a pedagogical space where stakeholders learn about genomics as they co-construct meanings of the data. As such, these spaces of convergence of POG instill and maintain the hopes of both the oncologists and the patients for personalized cancer treatments through the applications of clinical genomics.

This thesis is the Phase 1 of the longitudinal collaborative project with POG. The findings of the survey could feed back into the development of genomic education systems at POG. Moreover, the research team is planning to conduct interviews with survey respondents from Phase 1 in order to explore insightful views about the potential and challenges of genomics and POG along with the multidisciplinary collaboration between different medical stakeholders. The ultimate goal of the project is to illuminate profound values and strategies to improve physicians' genomic literacy that in turn promotes the integration of genomics into primary care. In sum, the findings shed light on the current level of genomic literacy among physicians in Western Canada. Physicians who locate outside metropolitan areas tend to have lower genomic knowledge than those who work in the city. More genomic training and workshop should be offered in regional areas to physicians who need more educational interventions. Initiatives like POG play a critical role in the education of MOs and the integration of big data clinical genomics into cancer care.

## **Implications of genomic literacy on communication and spaces of convergence**

The underlying mechanism of POG is the communicative and discursive processes involved in the meaning making of genomic information. Cancer clinical trial of POG is different from other genomic testing or profiling centers, where tests are simply being ordered by MOs, who then receive a report that must decipher the meaning of genomic data by themselves. At POG, it is a larger process of social interactions, discussions, and communication between different medical stakeholders at the POG

meetings that render the meanings of genomic data. Even though MOs are still the main actors determining the treatment options of cancer patients, whether it is based on the POG genomic results or not, the communicative and discursive processes taking place at the POG meetings may influence how MOs experience and evaluate the interventions. This highlights an important field of research for communication scholarship in studying the encoding and decoding processes of genomic information by different medical stakeholders. The line of this research could offer critical understanding of the knowledge production, public understandings of genomics, and actualization of clinical genomics through the lens of practices, communication processes, and situated epistemic cultures of the medical stakeholders.

Chow-White & Garcia-Sancho investigate the spaces of convergence, consisting of the spaces of flows of people, technology, and capital, at a macro and historical level of the first DNA sequencers to global genome databases. This thesis was only able to capture the spaces of flow of people, more specifically medical oncologists, with their disciplinary expertise and cultural values at a micro level of genomics in a specific context of a cancer clinical trial. The thesis presents an overarching narrative about the relationship and interaction between data scientists and domain experts who obtain different sets of knowledge in a traditional long-standing domain of clinical discipline. Using the concept of genomic literacy, I explore how the domain experts understand and interpret genomics data, and how their attitudes and experiences working with the technology can determine the adoption of genomics. One of the most significant outcomes of genomic literacy show how the domain experts, who tend to have a low level of genomic knowledge, are able to co-construct the knowledge and meanings of

genomic data through communicative and discursive processes with other medical stakeholders. This co-construction of genomic knowledge takes place within the spaces of convergence between computer scientists, biologists, genome scientists, and medical oncologists at the experimental clinical trial of POG. As such, POG represents an ongoing space of negotiation and communication where different medical stakeholders come together in these social constellations to co-produce the meaning of genomics. POG also acts as a pedagogical space for the medical stakeholders to learn and adopt the new style of practice engendered by genomic technologies, while creating meanings of the data. The social significance within the spaces of convergence of POG manifests the dominant logic of spatial, cultural, and informational structures of the network society in the context of clinical genomics.

This thesis explores the spaces of convergence of genomics at a micro level of a cancer clinical trial. In order to fully address the spaces of convergence of genomic data, future research can potentially examine genomics in the making by both human (multidisciplinary medical stakeholders) and non-human (technology, data, and codes) actors involved in the process of coding, analyzing, and converging biological nature of human vitality into informational structures of coding and algorithms. As Haraway (2004) notes, the co-construction of communication technologies and biotechnologies engenders natural-technical objects of knowledge that turns our flesh and soul into organic/machinic systems: “the ontology of databases and the marriage of genomics and informatics in the artificial life worlds reconstitute what it means to be human” (p. 278). At stake on the frontier of these spaces of convergence is precisely what will be consequences of the organic/machinic humans and how we can control this or not. And at

stake with the questions concerning the future of genomics are therefore not only what kind of human vitality and subjectivity will come after genomic technology, but also who will be part of the communication, discourse, or dialogue, that will shape and guide this process.

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## Appendix A.

### POG survey protocol

#### Title Page

You are invited to participate in this survey because you are one of the POG clinician investigators.

Our goal is to understand your experiences working with POG, how it impacted your clinical practice, and the program's value to the biomedical community as well as your understanding of genomics. The survey will take you about 20-30 minutes to complete. The results from the survey will help us improve POG and communicate its value to stakeholders outside the oncology/BCCRC community.

The survey is entirely voluntary and your participation will be anonymous and confidential. You can stop at any time and do not have to answer any questions you do not feel comfortable answering. The risks in participating are minimal to none. This research is being conducted under permission of the Simon Fraser Research Ethics Board [DORE #2014s0172]. The University and those conducting this research study subscribe to the ethical conduct of research and to the protection at all times of the interests, comfort, and safety of participants. The confidentiality of your participation will be maintained to the extent allowed by the law. The electronic research data will be stored in a private Canada-based server. Other research data and material will be stored in a locked file cabinet in the Faculty of Communication, Interactive Arts and Technology at SFU.

We appreciate you taking the time to complete the survey. If you have any comments, questions, or concerns about the survey please contact the principle investigator, Dr. Peter Chow-White, at [REDACTED]@sfu.ca

Q1 . What is your gender?

- Female
- Male
- Other

Q2 . How many years have you practiced oncology?



Years practicing oncology :  \*

Q3 . Which tumor group(s) do you primarily treat?

 \*

Q4 . Approximately how many new cancer patients did you have in the past year?

Number of new cancer patients :  \*

Q5 . Which BC Cancer Agency Centre are you in?

- Abbotsford Centre
- Centre for the North
- Centre for the Southern Interior
- Fraser Valley Centre
- Vancouver Centre
- Vancouver Island Centre

Q6 . How would you rate your knowledge of the following?

	No knowledge	Knowledgeable	Very knowledgeable	Expert
Basic genetic principles (i.e., inherited patterns) :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Newer genetic/genomic technologies (i.e., high-throughput sequencing, genotyping and copy number variation analysis) :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
The process of whole genome sequencing (i.e., features, eligibility criteria for sequencing, benefits, risks, and non-medical implications) :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q7 . How important do you think it is to improve your knowledge of clinical applications of genomics science and technologies?

- Unimportant
- Somewhat important
- Important
- Very important

Q8 . In your own experience, do you think there is enough genomics education or training in current medical curriculum?

Yes      No      Don't know

Undergraduate medical training (4-5 years) :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Specialized medical training (4-6 years depending on the specialty of training) :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Residency or Fellowship (2-5 years) :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Postgraduate medical training (3-5 years) :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q9 . Who should be responsible for updating medical oncologists about genomics?  
Select all that apply

- Canada's Michael Smith Genome Sciences Centre
- Ministry of Health Services
- Genome BC
- My Regional Health Authority
- Medical Schools
- Oncologists should update themselves
- Others

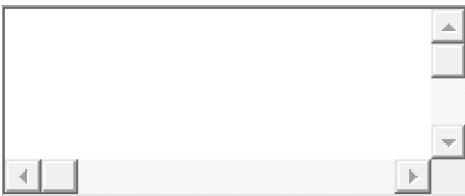
Q10 . If you think "Others" should be responsible, please describe them. Otherwise, please skip this question.

Q11 . How do you typically update yourself on genomics science? Select all that apply

- Consult colleagues and peers

- Mass media (TV, newspapers)
- Medical/Scientific journals
- Websites
- Continuing medical education (CME) accredited events
- Clinical rounds
- Residency or Fellowship
- Others

Q12 . If you have other ways, please describe them. Otherwise, please skip this question.



Q13 . How often do your patients ask about using genetic analysis to aid in diagnosis or treatment?

- Never
- Rarely
- Sometimes
- Always

Q14 . To your knowledge, have any of your patients used direct-to-consumer genetic testing?

- Yes

- No
- Don't know

Q15 . How much more frequent do you think the following will become in your practice within the next five years?

	Not more frequent	Somewhat more frequent	Much more frequent
Patients requesting genomic-assisted diagnosis and treatment choices :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patients using private or direct-to-consumer genetic testing :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q16 . In the next five years, how impactful will genomics be for the practice of medical oncology regarding the following?

	No impact	Minor impact	Major impact
Making a diagnosis :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Drug discovery :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Repurposing existing drugs :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Selecting course of treatment :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Transcriptome :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Whole genome sequencing :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Extending and improving lives :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
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Q17 . How concerned are you about the following issues related to expanding genomics science and technology into your practice? (i.e., whole genome sequencing, transcriptome, panel sequencing)

	Unconcerned	Somewhat unconcerned	Somewhat concerned	Very concerned
Clinical usefulness of genetic data (specificity/sensitivity/reliability) :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Extra effort without changing treatment :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Decision making on what results to return to patients :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Results leading to ineffective or harmful treatment :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Cost :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Immaturity of genomic science and technologies :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Patient comprehension of genomic science and technologies :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Unexpected germline findings :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q18 . How many patients in total have you referred for genomic sequencing via POG?

Number of patients :  \*

Q19 . What were your goals in partnering with POG? Select all that apply

- To find effective treatment
- To get access to a certain drug (ie., those currently under clinical trials)
- To learn more about genomics research

Q20 . As a result of POG, did you change any of your patients' management plans?

- Yes
- No

Q21 . If "Yes", then how many patients did you change the management plans based on the results from POG?

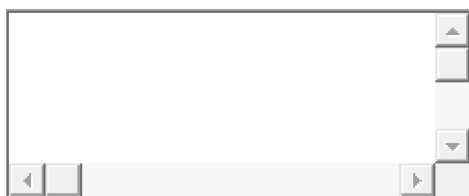
Number of patients :

Q22 . What concerns have you had in recommending treatments that were suggested by POG? Check all that apply

- POG did not recommend a drug for any of my patients
- None - I recommended the treatment options to patients
- Drug not approved for use or off label
- Drug underdeveloped or not accessible
- Drug too expensive
- I did not agree with the recommendation
- The patient was not comfortable with the recommendation

Others

Q23 . If you had other concerns, please describe them. Otherwise, please skip this question.



Q24 . To what extent do you agree with the following statements regarding your experience with POG so far?

	Strongly disagree	Somewhat disagree	Somewhat agree	Strongly agree
I feel more confident making treatment decisions after becoming informed about my patients' genome :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I feel confident that I could communicate POG results to my patients :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
POG added another layer of confirmation to existing indicators :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I had enough information and knowledge to understand the POG meeting and results :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I now want to apply tumour sequencing more often in my practice :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Meeting with the POG team was worthwhile :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>



I'm satisfied with my POG experiences :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I will collaborate with POG again :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Overall, POG is valuable to my practice :	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Q25 . Please describe which aspects of POG you find most valuable

◀
▶
\*

Q26 . How would you improve POG meeting?

◀
▶
\*

Q27 . Do you think POG should be publicly funded by the provincial government?

- Yes
- No

Q28 . Why or Why not?

◀
▶
\*

Q29 . Was there anything not asked about that you would like to give feedback on?

