

Silent Genomes: Gathering Ceremony Conference

Reducing health care disparities and improving diagnostic success for children with genetic diseases from Indigenous population

Conference Report

July 18-19, 2018

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Community Engagement Coordinator for Silent Genomes

October 2018



Silent Genomes: Gathering Ceremony Conference

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Territory Acknowledgement

We begin by acknowledging and respecting the traditional territory of the Lekwungen-speaking Peoples on whose traditional territories the Gathering Ceremony Conference was located on and the Songhees, Esquimalt and WSÁNEĆ peoples whose historical relationships with the land continue to this day.

We acknowledge our Elders who were in attendance, Elder May and Skip Sam and raise our hands to them for opening our conference in a cultural way and creating a safe space for our discussions. We are grateful to have witnessed the Lekwungen traditional dancers and Métis Jiggers and thankful to the diverse group of participants who were representing their Indigenous community and/or organization across Canada.

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Background

Silent Genomes is a 4-year, Genome Canada project funded by the Canadian Institute Health of Research [CIHR], Genome BC, Public Health Services Authority [PHSA], the BC Children's Hospital Foundation, the BC Children's Hospital Research Institute, and the Michael Smith Foundation for Health Research; Illumina and LifeLabs provided in-kind funding only. The goal of the project is to reduce health care disparities and improve diagnostic success for children with genetic diseases from Indigenous populations. The project emphasizes and promotes Indigenous-led governance, community engagement, community education, and student capacity building. It includes an International Indigenous Genetic Advisory Committee (IIGAC), a cross-country team of clinicians and genetic counsellors, local bioinformaticians, clinicians, and scientists with the collective goal of improving access and effectiveness of genetic diagnosis for Indigenous children. *Silent Genomes* is partnered with the Assembly of First Nations, the First Nations Health Authority (FNHA), the Métis National Council (MNC), and Inuit Tapiriit Kanatami (ITK) and includes 4 key activities:

- Activity 1: Integrating Indigenous-led governance, community engagement, community education, and student capacity building across all activities
- Activity 2: Precision genomic diagnosis of children with genetic disease
- Activity 3: Development of an Indigenous background variant library
- Activity 4: Economics of precision diagnosis for Indigenous children

Gathering Overview

'Gathering Ceremony', the launch of *Silent Genomes* was held in Victoria, BC on July 18th-19th, 2018. The purpose of this gathering was to bring together the *Silent Genomes* project team, the First Nations, Inuit, and Métis partners, and other stakeholders. Most importantly the goal was to gather insights and feedback on the project's most crucial and comprehensive activity, Activity 1- Community engagement, governance and capacity development.

There were 61 participants (57 in-person, 4 online via Skype). There was representation from National and Provincial Indigenous-run organizations, various First Nation communities across Canada, and a diverse range of National and International academic institutions.

The Gathering brought together participants with a diverse range of expertise including governance, capacity building, community engagement, and genetics and genomics on both a National and International level. The lead or co-lead presented on each activity which gave participants a chance to meet all members of the *Silent Genomes* team. There were also opportunities for participants to engage with other Indigenous researchers, community members and partners. Ensuring space for two-way communication, open-dialogues, and continuous conversations was important for the Gathering and will be maintained throughout the course of the project.



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Gathering Ceremony: Overview of *Silent Genomes* with Feedback

Activity 1: Integrating Indigenous-led governance, community engagement, community education, and student capacity building across all activities

Drs. Laura Arbour and Nadine Caron presented on Activity 1 which includes setting up the governance, but also includes the community engagement, policy development, and capacity building components. The first step in Activity 1 will be establishing and setting up the governance for the *Silent Genomes* project.

Community engagement: Collaboratively working with communities and partners on building the governance structures and educational materials. Ensuring there is reciprocal learning that establishes a cooperative understanding in all developmental components of the project.

Capacity building: Bringing additional students (medical, undergraduate, and graduate), interns (IMN-PN [Indigenous Mentorship Network of the Pacific Northwest], SING [Summer Internship for INdigenous Peoples in Genomics]) and the International Indigenous Genomics Advisory Committee participants as team members throughout the project.

Policy development: Identifying gaps in processes and policies to Indigenous genomics research that will be built into a deliverable policy model of guidelines and best practices. Leading Indigenous scholars with expertise in Indigenous genomics will compare governance models and dialogue on research ethics to work towards a consensus statement of Best Practices in the biomedical context when Indigenous peoples are involved.

Existing principles and guidelines that address Indigenous Peoples rights to self-determination, access, gaps, on-going community input, and research and ethics were brought up that will build a solid foundation for the standards for governance and guidance in policy. Inclusion of these guidelines were considered non-negotiable when building the governance for *Silent Genomes*.

- [United Nations Declaration of the Rights of Indigenous Peoples \(UNDRIP\)](#)
- [Truth and Reconciliation Commission \(TRC\)](#)
- [Ownership, Control, Access, and Possession \(OCAP\)](#)



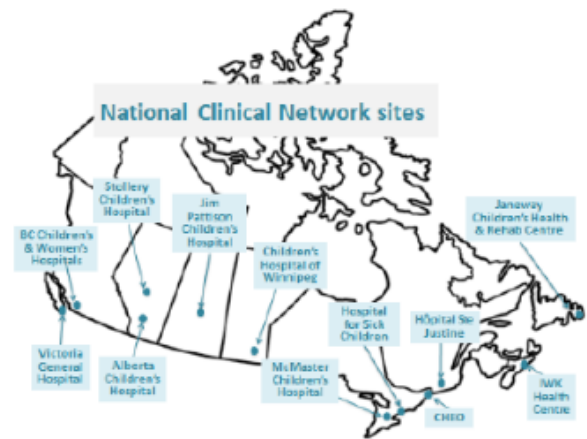
- [Tri-council Policy Statement \(TCPS\)-Chapter 9](#)

Of the four activities, Activity 1 is the fundamental component that oversees and surrounds all other activities of the project. Activities 2-3 have the potential to be integrated sustainably into health care; therefore, it was emphasized that it is essential that Activity 1 be structured to continuously evolve, guide, and influence all activities in perpetuity.

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Activity 2: Precision genomic diagnosis of children with genetic disease ('Precision Diagnosis study')

Drs. Anna Lehman and Maja Tarailo-Graovac presented on Activity 2, which will involve working with Indigenous families who have children with undiagnosed genetic disorders. There will be 12 clinical network sites throughout Canada and the goal is to enroll 200 families (15-20 from each site). Families enrolled for the precision diagnosis will be provided with culturally appropriate genetic counselling, state-of-the-art genomics diagnosis and clinically-confirmed results.



Background information was shared on 'CAUSES', a similar project to Activity 2 conducted through the BC Children's Hospital. This study also worked with families with undiagnosed genetic conditions and yielded a 47% diagnostic rate. Although the CAUSES project was similar in process, it was not Indigenous specific. It is possible that Activity 2 could yield similar or better results, however the outcome will also depend on the availability of reference data from Activity 3 (Indigenous Background Variant Library).

Activity 3: Development of an Indigenous Background Variant Library (IBVL)

Dr. Wyeth Wasserman presented on Activity 3, which will determine the genome sequence of an estimated 1500 Indigenous individuals across Canada to create an IBVL following the development of the established governance in Activity 1. It was proposed that participants could be invited into the IBVL from the following:

- Canadian Alliance for Healthy Hearts and Minds (the 'Alliance study') (900)
- Coastal Nations (200)
- Healthy relatives from Activity 2- Precision Diagnosis study (~400)
- Additional participants as funding and interest allows

The above is an estimation and will vary based on the participation from communities. The ultimate delivery of the IBVL will only happen if there is a shared desire for its creation and governance processes are acceptable and in place. If developed, the IBVL will be used as the reference library for Activity 2 (Precision Diagnosis study).

Questions from participants regarding the IBVL included how it would improve diagnosis, and the diversity of the library. The IBVL may improve diagnosis by serving as a reference for Indigenous populations who have not previously been represented in public reference databases. Although the interpretation of the variants in a patient's genome can still be analyzed without an IBVL, there may be more delays (because the population frequencies of variants are not known) or wrong diagnoses. There was clarification that the development of the IBVL would not be used to look at Indigenous genetic quantification, community comparison, or Indigenous population markers, but instead the genetic knowledge of genetic variation, only for the purpose of improving genomic diagnosis and health management, such as for Precision Diagnosis (Activity 2).

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Activity 4: Economics of precision diagnosis for Indigenous children

Dr. Dean Regier presented Activity 4, which will be unique to British Columbia and done in collaboration with FNHA. Along with the financial aspect of economics including labour, land, and capital, Activity 4 will also be characterizing the well-being of individuals and community values. The ‘diagnostic odyssey’ was one component that was thoroughly discussed because it ties both the financial and well-being aspects of economics. It was also hypothesized that the diagnostic odyssey may be prolonged and that there is an inequity of access between Indigenous children and non-Indigenous children. Activity 4 will take a mixed methods approach of both qualitative and quantitative research to characterize views, acceptability, harms and benefits. Focus groups, surveys and medical record reviews will be carried out to achieve the goals of Activity 4.

Summer Internship for Indigenous Peoples in Genomics (SING)

Drs. Ripan Malhi and Kim TallBear presented on SING, which is a one-week workshop that brings Indigenous students and community members together to learn about genomics by providing hands-on experience, integrative lectures, and discussion about the ethical, legal, and social implications of doing genomics with Indigenous communities. The first SING was held in 2011 and because of the program’s success the workshops are continuing to be held at different universities around the United States. This location shift has allowed a variety of special focuses with each workshop depending on the expertise of local Indigenous role models and mentors at each university, along with the core faculty of the founding Indigenous scholars.

There is also a New Zealand program, SING Aotearoa, initiated in 2016, and most recently, in July 2018 the first SING Canada was held at Simon Fraser University. There is interest in creating an Australian and South African SING. Due to the growing number of participant alumni and scholars from SING workshops, the SING Consortium was formed to discuss various topics on genomics research with Indigenous communities and provide insights into international Indigenous genomics perspectives. As part of Silent Genomes capacity building, we will provide support for a total of 36 students to attend SING workshops through a directed scholarship donated by LifeLabs Canada.

International Indigenous Perspectives on Genomics - IIGAC - International Indigenous Genetics Advisory Committee

The IIGAC International panel included Indigenous scholars from the United States, New Zealand, and Hawaii. The IIGAC panelists discussed Indigenous genetic/genomic initiatives within their own regions and their ways of addressing health disparities in an effort to close the gap, both in research and genetic health care.

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United States:

Dr. Garrison discussed a paper ([‘A Framework for enhancing ethical genomic research with Indigenous communities’](#)) that was developed through the SING Consortium, and at the time of the discussion was *in press*, soon to be published by Nature Communications. She provided a summary of the proposed key ethical considerations for engaging in genetics/genomics research with Indigenous Peoples and came up with six principles that were developed through learned experiences, mentors, family, and community members:

1. Understand tribal sovereignty and research regulation
2. Engage and collaborate with the tribal community
3. Build cultural competency
4. Improve transparency of research practices
5. Build tribal research capacity
6. Disseminate findings in a community-accessible format

The paper will help set the stage for ethical research practices for both researchers and tribal communities.

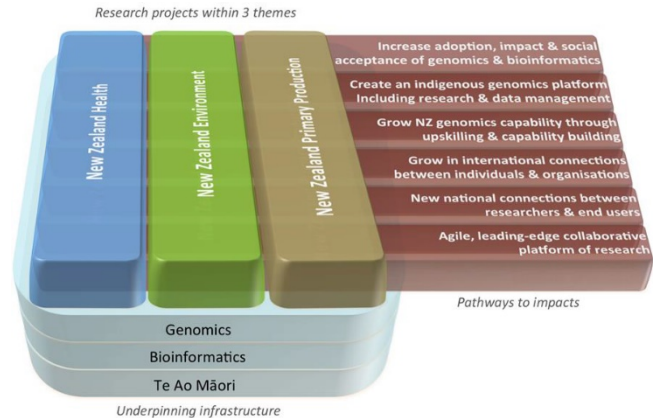
New Zealand:

Māui Hudson and Dr. Phil Wilcox discussed the development of an Indigenous Genomics Platform. The platform is in a similar stage as *Silent Genomes* in needing to build capacity around the ‘Te Ao Māori’ (Māori worldview) in genomics and engage communities. The platform is committed to bringing cultural considerations and partnering with Māori Peoples (including guardianship of data). The advisory group (Kahui Māori) consists of a diverse range of expertise ranging from business, law, cultural intellectual property, science, Māori policy, ethics, and genomics.

Hawaii:

Dr. Maile Taulii spoke about the Hawaiian community. She discussed the hesitations Native Hawaiian people may feel toward genetic research as they consider the relevancy to their community, peoples, and land, as well as the time, capacity and understanding for communities to contribute to research. She brought up the importance of learning how to bridge communication and translate community discussions to academia format. She shared the Native Hawaiian views on biobanking, G.R.E.A.T. Research (Governance, Re-consent, Education, Accountability, Transparency, and Research priorities) and also distributed a published article, [‘A Comparative Analysis of Indigenous Research Guidelines to Inform Genomic Research in Indigenous Communities’](#). She discussed the level of accountability that Indigenous researchers must have with the communities they work in. There are expectations that the research be carried out with the highest of ethical and scientific standards. This level of accountability should be generalizable to all researchers.

Following the presentations by the panelist, an open-dialogue with the group was started which brought up topics such as building cultural competency, safety, and humility. Insights on building cultural safety and humility were shared by the International panelists, FNHA, and the *Silent Genomes* team. A common



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theme amongst the discussion was ensuring that researchers are transparent and share the benefits and the challenges with communities. More importantly researchers need to convey cultural humility for discussions when not all cultural imperatives are understood.

Breakout Discussions

There were three breakout groups centered on Educational materials, Governance, and Policy where participants were able to provide advice and input. Participants chose which group they would be able to provide the best guidance for based on their expertise and experience or were most interested in. All groups had a diverse range of perspectives from community members, Indigenous leaders, researchers, and academics.

Education:

Two of the most important discussion points from the group were a query as to who the educational materials were for and that the *Silent Genomes* team needed to understand the unique protocols for approaching communities. It was shared that educational materials should be made available to not only patients, families, and communities, but as well for health providers, including the *Silent Genomes* Team (National Clinical Network), physicians, genetics counsellors, etc. Feedback from the communities and partners will be crucial for educational material development to ensure two-way dialogues and reciprocal learning.

Governance:

Governance was a complex topic for a breakout group because it will be the main foundation for all 4 Activities of the Silent Genomes Project. A good governance structure will lend itself to comparison of other Indigenous research guidelines for determining best practices, while providing flexibility for growth and development over the course of the project. Development must be collaborative and transparent. A key recommendation in the governance dialogue session focussed on the concepts of ‘partnerships,’ capacity development, and recognition that each Indigenous partner (First Nations, Métis, or Inuit) has a unique voice. Recognizing diversity within communities will ensure that key priorities are addressed in the governance structure. It will also ensure valuable inclusion of basic human and Indigenous Rights.

A good governance structure will provide enough flexibility to factor in future realities that are not yet part of the Indigenous genomic landscape. As suggested in the education group, the first step to structuring governance for the *Silent Genomes* project will be engaging with all partners.

Policy:

The Policy breakout group summarized key guiding opinions to be taken into consideration;

- Feasibility of data storage and biobanking located on Indigenous sovereignty territory
- A consent process that is tier-linked and structured to respect community
- Consolidating a ‘form policy’ that can be tailored to each community
- Access to IBVL involving responsibility and liability for a high ethical standard as it pertains to Indigenous health research standards including the requirement of self determination

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The group suggested to move from using the term ‘best practices’ to ‘wise practices’. They also discussed local examples and resources (i.e. FNHA, AFN), concepts for creating policy, bringing culture and spirituality into the project, and proper use of referencing and consent.

Closing

There were valuable stories shared and feedback for each activity throughout the day and a half conference. However, given the full agenda for the ‘Gathering Ceremony’ Conference there was still not enough space and time provided for in-depth open discussions following each presentation or closing remarks.

Moving forward, the *Silent Genomes* team will be compiling input shared from the breakout group discussions on the educational materials, governance, and policy. The breakout groups were vital for establishing the Indigenous voice for all three discussion topics, as well as include views and experiences from our partners and International Indigenous team. The guiding material that was shared within each breakout group will be brought back to the *Silent Genomes* team for further review and consideration.

The first step will be starting on the development of the educational materials and developing the process for how these material will be reviewed to ensure collaborative input from partners before distribution. Activity 2 is already getting started as there are known Indigenous families that would meet the criteria for the *Precision Diagnosis study*, and providing the option to participate could bring value to the patients, families and communities.

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Appendix

I. Agenda



*Silent Genomes:
'Gathering Ceremony'*

Tuesday July 17th
5:00pm – 9:00pm
Parkside Hotel- James Bay Room

- Pre-meeting and dinner with Alliance Study members

Wednesday July 18th
Royal BC Museum, Newcombe Hall
8:30am – 9:00am
Doors open- Coffee served

9:00am – 10:00am

- Opening Prayer and Welcome to Traditional Territory- Elder May Sam
- Lekwungen Traditional Dancers, Songhees Nation
- Participant introductions

10:00am-10:15am- *Break*

10:15am – 12:15pm
Continued Participant Introductions
Overview of *Silent Genomes* with feedback:
Introduction: Laura Arbour

- Activity 1: Nadine Caron
- Activity 2: Maja Taraillo-Graovac & Anna Lehman
- Activity 3: Wyeth Wasserman
- Activity 4: Dean Regier
- Discussion

12:15pm – 1:15pm- *Lunch*

1:15pm - 1:30pm
SING Workshops and *Silent Genomes* Life Lab
Scholarships: Ripan Malhi & Kim TallBear

Continued...



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Silent Genomes: 'Gathering Ceremony'

Wednesday July 18th continued

1:30pm – 3:30pm

International Panel: International Indigenous perspectives on Genomics- What are others doing around the world?

- Moderated by Nanibaa Garrison & Keolu Fox
- Speakers: Ngiare Brown, Maui Hudson, & Maile Taualii.

3:30pm – 4:00pm- Break

4:00pm – 5:00pm:

Open Discussion and closing.

6:45pm – 9:45pm

Parkside Hotel- City Club Lounge

- Dinner and Networking
- Traditional Métis Jigging and fiddling performance- Simone Blais and Wyatt Schiefelbein

Thursday July 19th

Royal BC Museum, Newcombe Hall

8:30am – 9:00am

Doors open- Coffee served

9:00am – 9:10am

- Opening Prayer and Welcome to Traditional Territory- Elders May Sam and Skip Sam

9:10am – 10:30am

Facilitated Group Discussions

- 1) Genomics Education Tools: What might work for the communities? What has been successful?
- 2) What will governance for the *Silent Genomes* Project look like?
- 3) What will long term policy look like?

Continued...

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Thursday July 19th continued

10:30am – 10:45am - Break

10:45am – 12:15pm
Large group reports and discussion

12:15pm – 12:30pm
Gathering Ceremony Closes
Elder Prayer- Elders May Sam and Skip Sam

12:30pm-1:30pm- Lunch

1:30pm – 4:00pm
International Indigenous Genomics Advisory Meeting



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Sault Ste. Marie, Ontario



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II.

PARTICIPANT LIST

Meeting: Gathering Ceremony Conference (Silent Genomes)	Date: July 18 th /19 th
Location: Victoria, BC	Room: Newcombe Hall

Name	Organization	Roles
May Sam	Elders	Tsartlip Nation
Skip Sam		Tsartlip Nation
Dr. Evan Adams	FNHA	Chief Medical Officer
Dr. Shannon McDonald		Deputy Chief Medical Officer
Celeta Cook		Regional Planner, Vancouver Island
Gillian Corless		Senior Advisor, Research and Ethics
Kevin Linn		Senior Policy Analyst Cancer/CPAC, Policy Planning and Transformation
Marilyn Dalton		Wellness Nurse Navigator, Regional Teams - Fraser Salish
Namaste Marsden		Manager, Research, Policy Planning and Transformation
Addie Pryce		Assembly of First Nations
Eduardo Vides	Métis National Council	Senior Health Policy Advisor
Sheila Carter		Director

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		Health & Wellness Department Manitoba Métis Federation
Bonny Graham	Canadian Alliance for Healthy Hearts and Minds	Maskwacis
Dr. Ellen Toth		Maskwacis- Site PI
Dipika Desai		Associate Program Manager, Population Health Research Institute
Bonnie Davis		Six Nations
Donna Banach		Lac La Ronge
Lisa Mayotte		Lac La Ronge
Dr. James Irvine		Lac La Ronge- Site PI (Skype participant)
Dr. Sylvia Abonyi		Lac La Ronge-Site Co-PI
Jean L'Hommecourt		Fort MacKay
Dr. Jeff Brook		Fort MacKay- Site PI
Jennifer Cameron		Pictou Landing
Natalie Denny		Pictou Landing
Heather Castleden		Pictou Landing-Site PI
Joanne Roulette		Sandy Bay
Virginia Lukianchuk		Sandy Bay
Julie Morrison		Gitxsan
Mavis Sebastian	Gitxsan	
Māui Hudson	International Indigenous Genomics Advisory Council	University of Waikato
Dr. Maile Taulii		University of Hawaii

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Dr. Phil Wilcox		University of Otago
Dr. Kim Tall Bear		University of Alberta (Skype participant)
Dr. Catalina Lopez	Genome BC	Chief Scientific Officer & Vice-President Sectors
Dr. Chen Wan		Sector Manager, Health
Jayce Sudweeks		Genome & Society Advisor
Dr. Earl Nowgesic	Canadian Institute of Health Research	Assistant Scientific Director, Institute of Indigenous Peoples' Health
Ellen Chesney	Provincial Health Services Authority	Chief Admin Officer, Research
Rebecca Lee	I HEART Centre (Indigenous Health Education Access Research Training) Providence Health Care	Research Manager, Programs and Strategic Planning
Dr. Laura Arbour	Silent Genomes	Project Leader UBC/UVIC
Dr. Nadine Caron		Co-Project Leader UBC/UNBC
Dr. Wyeth W. Wasserman		Co-Project Leader UBC
Dr. Anna Lehman		Co-Applicant UBC/BC Women's Hospital
Dr. Maja Tarailo -Graovac		Co-Applicant U. Calgary
Dr. Sonia Anand		Co-Applicant and NPI of Alliance. McMaster
Dr. Dean Regier		Co-Applicant UBC/BC Cancer Agency
Dr. Nanibaa' Garrison		Co-Applicant and IIGAC U. Washington/ Seattle Children's Research Institute (Skype participant)
Dr. Ripan Malhi		Co-Applicant U. Illinois

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Dr. Simon Gravel		Co-Applicant McGill
Dr. Josée Lavoie		Co-Applicant U. Manitoba
Dr. Jeff Reading		Advisor for Silent Genomes, Chair Heart Health Research SFU/FNHA/Providence Health
Leah Ballantyne		Policy Project Manager
Dr. Irina Manokhina		Scientific Project Manager
Sarah McIntosh		Genetic Counsellor-Victoria
Karen Jacob		Genetic Counsellor- Vancouver
Brittany Morgan		Community Engagement Coordinator
Laurie Montour		Community Engagement Coordinator
Lawrence Gillman		Research assistant
Chenoa Cassidy-Matthews		PhD student- Activity 4
Dora Pak		Financial project manager