

Giant Mine Remediation Project Health Effects Monitoring Program

Guiding Principles

November 2018

PROJECT SUMMARY

Purpose: The purpose of the Health Effects Monitoring Program is to establish baseline levels of contaminant exposure and examine possible health effects among residents in Ndilo, Dettah, and Yellowknife in the Northwest Territories, before remediation work begins. Then, during remediation, new monitoring results will be compared to the baseline to ensure participants' arsenic levels are not increasing because of work being done at Giant Mine. The monitoring program will focus on arsenic, and other Contaminants of Potential Concern (COPCs) such as cadmium, lead, manganese, antimony and vanadium which may be released as a result of the remediation project.

Context: The Giant Mine is an inactive gold mine located within the City of Yellowknife boundary, where it operated from 1948 to 2004. The site reverted to the Crown when owner Royal Oaks Mine went into receivership in 1999. At present, the mine is considered one of the most contaminated sites in Canada. To address concerns about arsenic and other contamination, a Giant Mine Remediation Project (GMRP) was established. The main objectives of the GMRP are to: minimize public and worker health and safety risks, minimize the release of contaminants from the site to the surrounding environment, remediate the site in a manner that instills public confidence, and implement an approach that is cost-effective and robust over the long term. Indigenous and Northern Affairs Canada (INAC) and the Government of the Northwest Territories (GNWT) are co-proponents of the Giant Mine Remediation Project.

Why a monitoring program: In 2014, the Mackenzie Valley Environmental Impact Review Board completed its seven-year assessment of the GMRP to address public concerns about the impact the mine's clean-up activities may have on the local population's health. One of the requirements by the Review Board was to design and implement a Health Effects Monitoring Program in Ndilo, Dettah and Yellowknife. The purpose of the monitoring program is to make sure the remediation activities that will take place at Giant Mine will not have a negative impact on people's health.

Stakeholders: Dr. Laurie Chan, a toxicologist from the University of Ottawa, is the lead researcher on the Monitoring Program. In order to engage with a variety of affected stakeholders, a Health Effects Monitoring Program Advisory Committee (HEMPAC) was created as a mechanism for member groups to contribute to the development and implementation of the Monitoring Program by utilizing their health expertise and knowledge of regional and community level issues.

HEMPAC meets once a month and consists of the following representatives:

- Indigenous and Northern Affairs Canada (INAC)

- Government of Northwest Territories Department of Environment and Natural Resources (GNWT ENR)
- Government of Northwest Territories Department of Health and Social Services (GNWT HSS)
- Health Canada (HC)
- City of Yellowknife
- Yellowknives Dene First Nation (YKDFN)
- North Slave Métis Alliance (NSMA)
- Giant Mine Oversight Board (GMOB)
- University of Ottawa (uOttawa)

With additional support from: Institute for Circumpolar Health Research.

The project will also enlist the help of other experts and professionals as well as part-time researchers to aid in the implementation of the monitoring program including:

- Dr. Ken Reimer of the Royal Military College as an external expert reviewer.
- Dr. Harriet Phillips of Can North, project lead on the Human Health and Ecological Risk Assessment study. HHERA will provide information on water, animals and soil, and the human health risk associated with Giant Mine.
- Sharen Roland of Génome Québec who will aid in DNA analysis.
- Rossana Manriquez and Jean Dumais of Statistics-Canada, who will aid in developing a sampling methodology.
- Susan Chatwood of the Institute for Circumpolar Health Research, who will aid in finalizing Research Partnership and Data Sharing Agreement, and access to medical records with the NWT Health Authority. Susan will also provide mentorship to a Coordinator based out of the ICHR office, and who will work for and represent the study in Yellowknife.

Funding: Funding for the Monitoring Program is provided by Indigenous and Northern Affairs Canada through the Giant Mine Remediation Project.

Tentative plan: Interviews and sample collection will begin in the fall 2017 with approximately one thousand participants from age 6 to 79 and Elders, from Ndilo, Dettah, and Yellowknife. Sample collection will continue in the spring 2018 with another one thousand participants from age 3 to 79 and Elders, for a total of approximately two thousand. The participation age was lowered to 3 years of age to complement the Canadian Health Measures Survey, and to increase the potential number of children participants in the study.

Residents of Yellowknife will be randomly selected from the City of Yellowknife housing list. Members from the Yellowknives Dene First Nation (Yellowknives Dene) and North Slave Métis Alliance (NSMA) will participate on a voluntary basis. Each participant will be asked to complete a lifestyle and food frequency questionnaire, and provide samples of toenail clippings, and urine for contaminant testing. Members of the Yellowknives Dene First Nation members will also be asked to answer a medical history questionnaire and undergo a brief medical exam by a registered nurse. Participants will also be asked to provide a sample of their saliva, taken with a buccal swab on the inside of their cheek, to test for 20 specific genes that are known to interact with arsenic. Analysis of these specific genes and the single nucleotide polymorphisms associated with them will provide insight on how the genetic makeup of study participants may affect their interaction with arsenic. Studies have shown that some ethnicities may metabolize arsenic more efficiently. In addition, all participants will be asked to provide consent to have their medical records reviewed for the past five years. Precautions will be put in place to protect participant's privacy. A follow-up study with youth participants (ages 3 to 17 at the time of data collection in 2017-2018) will be invited to participate in a follow-up study in 2022/2023. A follow-up study for all participants, including adults is planned for 2027/2028.

Main components of the Monitoring Program include:

- Lifestyle Questionnaire
- Food Frequency Questionnaire
- Biological sampling of toenail clippings, urine and saliva
- DNA Analysis of saliva
- Review of medical records, for the past 5 years
- Medical History Questionnaire and medical exam (weight, height, blood pressure) by a registered nurse (YKDFN members only)

Each participant will be provided with their individual test results in a personal letter with appropriate medical advice. Medical record data will ONLY be used to investigate possible associations between contaminant exposure and specific health outcomes at the population level.

Benefits: The Health Effects Monitoring Program will provide participants an opportunity to find out whether they are currently exposed to arsenic, and other metals of concern such as cadmium, and lead. The overall results could also contribute to a bigger picture of local exposure to contaminants in and around Dettah, Ndilo, and Yellowknife.

The monitoring program will be guided by the principles of the Tri-Council Policy Statement and Ownership as developed by the Canadian Institutes of Health Research, the Natural Sciences and Engineering Research Council of Canada and the Social Sciences and Humanities Research

Council of Canada, and by the Ownership, Control, Access and Possession Principles (OCAP) as developed by the National Aboriginal Health Organization.

SECURITY OF DATA

The data collected (questionnaires, toenail clippings, urine and saliva) will be kept in a secure manner (in a computer in a locked room at the University of Ottawa) until completion of the program. The Principal Investigator, along with some authorized research students, will have access to the data. The data will only be used for the purpose of this study. A copy of the master database shall be provided to the Institute for Circumpolar Health Research once data collection is complete. Both institutions will be responsible for retaining the complete dataset until completion of the program in approximately 2029.

In addition, a biobank will be established to archive sub-samples of urine and toenail clippings collected from the participants in a -80°C freezer in a secure room at the University of Ottawa. These samples will allow for analysis of other contaminants, such as mercury, that may be of concern in the future. Individuals will be asked to consent to whether the study can store their samples in a biobank.

PURPOSE OF THE GUIDING PRINCIPLES

The purpose of the Guiding Principles is to provide written instruction on regular and recurring work processes to be performed by the Health Effects Monitoring Program team. The Guiding Principles also contains overall summaries from other key documents including the Communications and Engagement Plan, and HEMPAC Terms of Reference; job descriptions for key staff members; and an overall timeline of activities for the program.

This is a working document which will get updated as new information becomes available.

RESPONSIBILITIES

1. **Health Effects Monitoring Program Advisory Committee (HEMPAC):** provide technical expertise; regional and community perspectives; as well as feedback on key program documents and communications materials.
2. **Principal Investigator (Laurie Chan, uOttawa):** provides leadership and assumes overall responsibility on all aspects of the project including the scientific merit, training, finance and management, ethics and bias, community engagement and dissemination of results.

3. **Health Canada:** member on HEMPAC; in addition to providing technical and scientific expertise, Health Canada will provide most up to date reference numbers for COPCs.

Implementation Team

4. **University of Ottawa:**

Project Manager (Renata Rosol): Manages day-to-day program administration, budget and logistics; coordinates monthly HEMPAC meetings; develops communication materials, plans, and implements all activities related to the program (*part-time/full-time during data collection periods; detailed job description on p.23*).

Doctoral/Masters/Summer students (s): Conduct background research; provide feedback on program-related documents; help with preparation of training manuals and training; responsible for quality assurance/quality control during data collection; conduct laboratory and data analysis and write-up papers.

Data analyst: Develop secure tablet-based interview instrument, convert data into database, manage database, and conduct data analysis.

Contractors: House and manage program website; edit key documents.

5. **Assistant Coordinator (based out of office at ICHR in Yellowknife):** Will be hired locally and work closely with Project Manager to help coordinate and implement the Health Effects Monitoring Program in Yellowknife; attend events; assist with program communications; organize community meetings; assist in hiring local staff for data collection; provide support to research assistants/nurses; and assist with other logistical and administrative tasks as necessary (*part-time/full-time during data collection periods; detailed job description on p.25*).
6. **Community Project Coordinator:** Will be hired locally and work closely with YKDFN stakeholder and Project Manager to help communicate and implement the Health Effects Monitoring Program in Ndilo and Dettah; communicate with members to promote participation in the study; set-up appointments for members with trained research nurses (*job description finalized with YKDFN leadership in June 2017, p.26*).
7. **Government of Northwest Territories Department of Environment and Natural Resources (Erika Nyssonen):** Co-proponent of Giant Mine Remediation Project;

provides guidance and feedback on all aspects of planning and implementation of the monitoring program; member of HEMPAC.

8. **Indigenous and Northern Affairs Canada (INAC - Jane Amphlett, Natalie Plato, Myranda Bolstad, Geneva Irwin):** Lead department responsible for the Giant Mine Remediation Project; approvals and funding of the monitoring program; overall responsibility for ensuring program meets requirements of the GMRP Environmental Assessment (Measure 9); as member of HEMPAC will provide guidance and feedback on all aspects of planning and implementation of the program; INAC will take the lead on the overall communication and engagement plan. INAC will also provide technical support for social media communications such as twitter and Facebook.

9. **Institute for Circumpolar Health Research (Susan Chatwood):** Help prepare data management and medical files access plan with NWT Health Authority; provide mentorship to Yellowknife-based Assistant Coordinator working out of ICHR; provide office space.

TIMELINE & ACTIVITIES FOR HEALTH EFFECTS MONITORING PROGRAM

Month	Activity	People Involved	Tasks
JANUARY 2017			
PLANNING PHASE: JANUARY TO AUGUST 2017			
January-June 2017	Incorporate comments from stakeholders for Research Plan	uOttawa, HEMPAC	<ul style="list-style-type: none"> - Develop Proposal and seek feedback/comments from HEMPAC members (<i>deadline extended to June 9</i>) - Final Plan: to complete after community meetings in Yellowknife and Dettah in April 26-27
February - (on-going)	Prepare Guiding Principles document	uOttawa, HEMPAC	<ul style="list-style-type: none"> - Document outlining main activities for first year of the Program and people responsible for them - Activities will be updated as program moves from one year to the next
March	Budget	uOttawa, INAC	<ul style="list-style-type: none"> - 1st year budget separated into 2 phases (planning & implementation) - INAC to approve Contribution Agreement with uOttawa and provide funding for Program planning phase - Contribution Agreement prepared yearly
March-June (on-going)	Communications Plan	Giant Mine Project, uOttawa, HEMPAC	<ul style="list-style-type: none"> - Initial draft - Receive feedback from HEMPAC by May
April 7	Logo development	INAC Communications/ Engagement, uOttawa,	Final logo

Month	Activity	People Involved	Tasks
April 7	Brochure	uOttawa, INAC Communications/Engagement	English Wiiliideh (to be finalized in June)
April 7	Poster	uOttawa, INAC Communications/Engagement	- General information (best size 8 ½ x 11, to fit on poster boards)
April 7	Radio Ads in Yellowknife	uOttawa	<p>Moose FM- CJCD (Radio station, broadcasts in Yellowknife and Hay River) Contact: raram@vistaradio.ca or use a web form at http://www.myyellowknifenow.com/advertise-us/</p> <p>CKLB Radio (Radio station run by the Native Communications Society, broadcasts out of Yellowknife into multiple communities) Contact: news@cklbradio.com</p> <p>CBC North –drop off PSA in person</p>
April 7	Newspaper Ads in Yellowknife	uOttawa	<p>Northern News Services Limited (publishes News North on <i>Mondays</i>, Yellowknifer on <i>Wednesdays</i>, <i>Fridays</i>) Contact advertising@nns.com</p> <p>YK Buzz to put event on their calendar: http://ykbuzz.com/</p>
April 13	Presentations x 3	uOttawa	<ul style="list-style-type: none"> - Community meetings - One draft for YK residents, YKDFN, and NSMA
April 13 (on-going)	Website development (www.ykhemp.ca)	Project Manager	<ul style="list-style-type: none"> - Final layout - On-going maintenance throughout length of program


Month	Activity	People Involved	Tasks
April 13	Recruitment Letter	uOttawa	<ul style="list-style-type: none"> - Final draft - Include with Ethics application - Letters will be sent by mail or delivered in person in the Fall
April 26	Community meeting with NSMA in Yellowknife	uOttawa, Giant Mine Project, others	<ul style="list-style-type: none"> - Organize initial community meeting to inform about program and seek feedback on Plan <p><i>Subsequent meetings will be organized in September to recruit volunteer participants.</i></p>
April 27	Community meeting with YKDFN in Dettah	uOttawa, Giant Mine Project, others	<ul style="list-style-type: none"> - Organize initial community meeting to inform about program and seek feedback on Plan <p><i>Subsequent meetings will be organized in September to recruit volunteer participants.</i></p>
April 27 (evening)	Public meeting w/YK residents in Yellowknife	uOttawa, Giant Mine Project Team, others	<ul style="list-style-type: none"> - Inform residents about program and seek feedback on Plan
May	Hire Assistant Coordinator	ICHR, uOttawa	<ul style="list-style-type: none"> - Assistant Coordinator based out of office at ICHR (part-time & full-time from Sept to Dec 2017) - Will work closely with Project Manager to help with communications, planning and implementation of YKHEMP in Yellowknife
June-July	Develop job posting and hire a Yellowknife-based Community Project Coordinator	Project Manager, YKDFN	<ul style="list-style-type: none"> - Community Project Coordinator will be the main point of contact for YKHEMP in Yellowknife as we move forward with the study. - Position will include two main

Month	Activity	People Involved	Tasks
			<p>tasks: 1. Work for and be the local face of YKHEMP; and 2. Search and organize YKDFN archives related to Giant Mine.</p> <ul style="list-style-type: none"> - Will work closely with YKDFN & Project Manager to help with communications, planning and implementation of the Program in Ndilo and Dettah during data collection
FINALIZE KEY PROGRAM DOCUMENTS			
May-June	1. Research Plan	uOttawa, HEMPAC, YK / YKDFN / NSMA community input	<ul style="list-style-type: none"> - HEMPAC members provide input and written comments - YK, YKDFN and NSMA provide additional feedback through April community meetings - INAC approve Contribution Agreement with uOttawa and provide funding for the Implementation Phase once all key documents approved and ethics approval received
May 1-3	2. Ethics	uOttawa	<p>Submit ethics application to uOttawa. Laurie signature.</p> <p>Office of Research Ethics and Integrity Tabaret Hall Room 154 Tel: 613-562-5387 ethics@uottawa.ca</p>
May 10	3. NWT Scientific Research License	uOttawa	<ul style="list-style-type: none"> - Submit application through Aurora Research Institute (Inuvik-based research centre) <p>http://nwtresearch.com/licensing-</p>

Month	Activity	People Involved	Tasks
			research <ul style="list-style-type: none"> - Submit online 3 mo. in advance of study
June 9	4. Communications & Engagement Plan	uOttawa, HEMPAC	<ul style="list-style-type: none"> - HEMPAC to provide additional input
June	5. Sampling Plan	Stats Can, uOttawa	<ul style="list-style-type: none"> - Finalize sampling protocols w/Statistics Canada - Assistant Coordinator and research team will physically check and confirm apartment units in some multi-level complexes - Stats Can develop manuals with sampling protocols - Draft final Sampling Plan
June-August	6. Data Management & Sharing Agreement	uOttawa, ICHR, HEMPAC	<ul style="list-style-type: none"> - Draft sent out to HEMPAC for input, deadline for comments April 4-7. - Final version <p>3rd parties seeking access to the data will have to go through HEMPAC for approval</p>
June	7. Memorandum of Understanding (MOU)	ICHR, uOttawa	<ul style="list-style-type: none"> - Set up an MOU between uOttawa and ICHR
June (may take up to 1 year)	8. Access to Medical Records Plan	ICHR, uOttawa	<ul style="list-style-type: none"> - ICHR will work with the NWT Health Authority on an agreement that will allow uOttawa to access medical files (for those individuals who provide consent).
June	9. Letters of Support	ALL	<ul style="list-style-type: none"> - Organizations to provide a Letter of Support expressing their backing for this study and its research protocols

Month	Activity	People Involved	Tasks
			<ul style="list-style-type: none"> - To address to Dr. Laurie Chan - Letters will be sent with the final Research Plan to INAC
June-September	Meeting w/GNWT Health Authority staff?	Susan, Laurie	<ul style="list-style-type: none"> - Laurie to present final Plan, if necessary - Obtain letter of support from NWT Health Authority
June-September	COMMUNICATION S	uOttawa, INAC, Assistant Coordinator, GMOB	<p>On advice of GMOB: Door to door distribution and sharing of information could be the difference between great success and mediocre achievement.</p> <p>Pre-study period needs at least 2-3 months to set in the story of what it is going to do and how it is going to do it with the community messaging system. (For example, sponsor ads in local newspaper to tell people they might receive invitations to join the study.)</p>
July-August	1 st Newsletter to share in Yellowknife, Ndilo and Dettah	uOttawa, HEMPAC	<ul style="list-style-type: none"> - Communicate key issues brought up during April community meetings, and our plan to address them - Share with the general public - Send a letter to Yellowknife Counselors and MLAs
July-August	Set-up Youth Visits to GMOB office in YK	Assistant Coordinator, GMOB	<ul style="list-style-type: none"> - Start informing youth about the upcoming Health Effects Monitoring Program
June-August	Attend Events in YK, as necessary	Assistant Coordinator, uOttawa, INAC	<ul style="list-style-type: none"> - Take part in local events as much as possible to create opportunities to communicate about the upcoming YKHEMP in the fall.

Month	Activity	People Involved	Tasks
PREPARATIONS FOR DATA COLLECTION			
June-July	Develop template-based questionnaire	Questionnaire Software Developer	<ul style="list-style-type: none"> - Part-time contractor to design software application for the tablets to be used during data collection - Provide technical support during data collection
June-August	Hire Contract Staff in YK	Project Manager, Assistant Coordinator, Susan	<ul style="list-style-type: none"> - Recruit & hire the following personnel in YK and sign contracts (Sept-Dec 2017): <ul style="list-style-type: none"> o 12x Research Assistants (RAs) o 2x Nurses - Create job descriptions & advertisements - Screening and interviewing of potential RAs
June-August	Develop Field Procedure Manuals	uOttawa	<ul style="list-style-type: none"> - Prepare data collection protocols - Metal fact sheets on As, Cd, Pb
July	Field Test Questionnaires & Sampling manual in Yellowknife	uOttawa, Assistant Coordinator	<ul style="list-style-type: none"> - Test out questionnaires on tablets with some HEMPAC stakeholders - Conduct a small pilot with local residents, nurses, stakeholders in YK to ensure understanding, ease of use of data collection protocols, recruitment strategy etc.
August	METHODOLOGY WORKSHOP	HEMPAC stakeholders	<ul style="list-style-type: none"> - In-person meeting in Yellowknife to finalize all study protocols, logistics, communications with all HEMPAC stakeholders
August	Data collection	uOttawa, Assistant	<ul style="list-style-type: none"> - Study equipment will be stored at ICRH and biological

Month	Activity	People Involved	Tasks
	supplies: - Lab Kits (buccal swab, urine, nail collection) - Tablets x20 - Coolers to ship urine samples in - Tub/box to ship other materials	Coordinator 	samples at Taiga lab until ready for shipping to uOttawa (toenails, urine) or Genome Quebec (buccal swabs) - Continue to promote program through radio, newsletter releases, posters, brochure to help raise awareness of the program
August	Hired Community Project Coordinator	Project Manager	- Developed a Funding Transfer Agreement between uOttawa and YKDFN to cover salary for Community Project Coordinator - Community Project Coordinator will be a full-time employee for YKHEMP based out of Ndilo. Will be the main point of contact for YKHEMP. - Other main task will include review of YKDFN archive records. - Will work closely with Project Manager based out of uOttawa.
IMPLEMENTATION PHASE – WAVE 1 Data Collection: Sept-Dec 2017			
August-September	Random selection of YK resident participants	Stat Can, uOttawa	- Use Statistics Canada sampling plan to randomly select up to 750 Yellowknife residents - Send recruitment letter
September	Send Recruitment Letters to randomly selected YK residents, all YKDFN and	Project Manager, Assistant Coordinator, Community	- Recruitment letters will be mailed to randomly selected individuals in Yellowknife

Month	Activity	People Involved	Tasks
	NSMA households	Project Coordinator, YKDFN youth	<ul style="list-style-type: none"> - NSMA stakeholder will send letter and brochure via email to all its' members - Recruitment letters will be delivered in person to all YKDFN households in Ndilo and Dettah - Include a brochure
September	TRAINING (for Data Collection)	Project Manager + Training Coordinator + Community Project Coordinator + Assistant Coordinator	<ul style="list-style-type: none"> - Training will take place at Arctic College: <ul style="list-style-type: none"> o get familiar with questionnaires and using the tablet to input data o protocols for collection, handling & storage of biological samples o finance, admin details - 2 day training for Research Assistants - ½ day training for Nurses
September	Publicize the Program in Yellowknife, Ndilo and Dettah	uOttawa (Renata, Laurie), INAC, Assistant Coordinator, Community Project Coordinator, HEMPAC input	<ul style="list-style-type: none"> - Distribute posters, brochure in Yellowknife, Ndilo and Dettah - PSAs on local radio, newspapers - Social media (Facebook) - Update GMRP and YKHEMP websites - Local and national media
September-December	DATA COLLECTION - Yellowknife residents - Lifestyle questionnaire	12x Research Assistants (RAs) Project Manager Field Coordinator (<i>selected one of</i>	<p>ALL: program team will be available to assist and support community data collection.</p> <ul style="list-style-type: none"> - Follow up at the residence to invite an adult (18-79) and a

Month	Activity	People Involved	Tasks
	<ul style="list-style-type: none"> - Food Frequency Questionnaire - Biological samples: toenails, urine and saliva with a buccal swab 	<i>the RAs)</i>	<ul style="list-style-type: none"> child (6-17) whose birthday is coming up next, get consent & set up an appointment - Interview about 750 YK residents (<i>min. 35 participants per RA</i>) - Visit to last about 45 minutes - Field Coordinator keeps track of samples in Yellowknife, and Household Status spreadsheet - Project Manager to travel to YK every 2 weeks to pick up samples and meet with field staff
September-December 11	<p>DATA COLLECTION – NSMA members (same as above)</p>	1x Research Assistant, Assistant Coordinator, Project Manager	<ul style="list-style-type: none"> - Recruitment meetings to find volunteer participants (50 members) - Ages 6+ - Visit to last about 45 minutes
September-December 11	<p>DATA COLLECTION - YKDFN</p> <ul style="list-style-type: none"> - Lifestyle Questionnaire - Food Frequency Questionnaire - Biological samples : toenails, urine, saliva with a buccal swab - Medical Questionnaire - Basic medical check-up 	2x Nurses Community Project Coordinator, YKDFN, Project Manager	<ul style="list-style-type: none"> - Recruitment meetings to find volunteer participants (150-200 members) - YKDFN Coordinator will work closely with the nurses to help schedule appointments at participant’s home or other location, as necessary - Ages 6+ - Visit to last about 60 minutes <p><i>If certain demographic or household is lacking, that demographic or household will be contacted and invited to participate through a letter, call or house visit.</i></p>

Month	Activity	People Involved	Tasks
December 11	Last day to ship samples to uOttawa or Génome Quebec	Field Coordinator, Project Manager	Urine samples to be kept in the fridge at 4°C at Taiga lab until ready for shipping: To uOttawa: toenail clippings, urine samples To Génome Quebec: buccal swab w/saliva
JANUARY 2018			
January <i>(ongoing)</i>	DATA ANALYSIS continues	uOttawa, Génome Quebec	<ul style="list-style-type: none"> - All urine and toenail clippings samples at uOttawa lab - All saliva samples at Genome Quebec lab - Data cleaning and analyses
February	Research Ethics Committee	uOttawa	<ul style="list-style-type: none"> - NWT Health Authority asked YKHEMP to apply for a Research Ethics Certificate from the Aurora College Research Ethics Committee as part of the process to help finalize a Research Agreement for access to medical records - Certificate of Ethics Approval granted in May 2018 - Apply for an annual Certificate of Ethics Approval for the duration of the study
IMPLEMENTATION PHASE – WAVE 2 Data Collection: April-June 2018			
Jan-April	Supplies	uOttawa, YK Coordinator	<ul style="list-style-type: none"> - Ensure all supplies needed are in Yellowknife for 2nd wave of participant sampling
February	Random selection of YK resident participants	Stat Can, uOttawa	<ul style="list-style-type: none"> - Use Statistics Canada sampling plan to randomly select up to 750 Yellowknife

Month	Activity	People Involved	Tasks
			<p>residents</p> <ul style="list-style-type: none"> - Send or deliver a recruitment letter
March	Hire Contract Staff in YK	Project Manager, Assistant Coordinator	<ul style="list-style-type: none"> - Recruit & hire the following personnel in YK and sign contracts (Apr-Jun 2018): <ul style="list-style-type: none"> o 18x Research Assistants (RAs) o 3x Research Nurses - Create job descriptions & advertisements - Screening and interviewing of RAs
early April	Send Recruitment Letters to YK residents	Project Manager, Community Project Coordinator, Assistant and Field Coordinators	<ul style="list-style-type: none"> - Recruitment letters were mailed to randomly selected individuals (about 1100) in Yellowknife OR dropped off in person - Include 8 ½ x 11 study poster developed specifically for 2018 data collection
April	TRAINING (for Data Collection)	Project Manager, Community Project Coordinator, Field Coordinator	<ul style="list-style-type: none"> - Training will take place at Yellowknife United Church, Room 205: <ul style="list-style-type: none"> o get familiar with questionnaires and using the tablet to input data o protocols for collection, handling & storage of biological samples o finance, admin details - ½ day training for returning Research Assistants and Nurses - 1-day training for new Ras

Month	Activity	People Involved	Tasks
April	COMMUNICATIONS for YKHEMP in Yellowknife, Ndilo and Dettah	Project Manager, Community Project Coordinator, Field and Assistant Coordinators	<ul style="list-style-type: none"> - Distribute posters, brochure in Yellowknife, Ndilo and Dettah - PSAs on local radio, newspapers - Social media - Update GMRP and YKHEMP websites - Local and national media
April-June	<p>DATA COLLECTION - Yellowknife residents</p> <ul style="list-style-type: none"> - Lifestyle questionnaire - Food Frequency Questionnaire - Biological samples: toenails, urine and saliva with a buccal swab 	<p>18x Research Assistants (RAs)</p> <p>Project Manager, Field and Assistant Coordinators, Community Project Coordinator</p>	<p>ALL: program team will be available to assist and support community data collection.</p> <ul style="list-style-type: none"> - Follow up at the residence to invite an adult (18-79) and a child (3-17) whose birthday is coming up next, get consent & set up an appointment - Interview about 750 YK residents (<i>min. 35 participants per RA</i>) - Visit to last 30-45 minutes
April-June	<p>DATA COLLECTION – NSMA members (same as above)</p>	<p>1x Research Assistant, YK Coordinator, uOttawa</p>	<ul style="list-style-type: none"> - Emails sent to all members to find volunteer participants (about 50 members) - Ages 3+ - Visit to last 30-45 minutes
April-June	<p>DATA COLLECTION - YKDFN</p> <ul style="list-style-type: none"> - Lifestyle Questionnaire - Food Frequency Questionnaire - Biological samples : toenails, urine, saliva 	<p>3x Nurses</p> <p>Community Project Coordinator, Field and Assistant Coordinators</p>	<ul style="list-style-type: none"> - Organize activities to find volunteer participants (about 150-200 members) - Community Project Coordinator will work closely with the nurses to help schedule appointments at participant's home or other location, as necessary

Month	Activity	People Involved	Tasks
	with a buccal swab - Medical Questionnaire - Basic medical check-up		- Ages 3+ - Visit to last about 60 minutes <i>If certain demographic or household is lacking, that demographic or household will be contacted and invited to participate through a letter, call or house visit.</i>
May	Renew uOttawa Ethics, Aurora College Scientific Research License and Certificate of Ethics	uOttawa	- Renew for every year of the study - Scientific Research License is renewed by December of each year.
June 28	Last day to ship samples to uOttawa or Génome Quebec	Field Coordinator, Project Manager	Urine samples to be kept in the fridge at 4°C at Taiga lab until ready for shipping: To uOttawa: toenail clippings, urine samples To Génome Quebec: buccal swab w/saliva
June-July	Send individual results to WAVE 1 of participants	uOttawa, HEMPAC, GNWT HSS	- Personal letters are sent out to participants with explanation of their results (urine only) - Nurse Practitioner in place to answer questions, conduct follow-up blood tests and questionnaire for participants with metal exceedance for As, Cd and/or Pb
July	Hire Medical Researcher	Project Manager	- Hire a person familiar with Wolf EMR system and with access to the system
September	Research Agreement with NWT Health Authority	Project Manager, GNWT HSS and Privacy Office	- Research Agreement finalized in September 2018 - It took about 1 year to finalize a Research Agreement with

Month	Activity	People Involved	Tasks
			the GNWT Health Authority in order to gain access to medical files for consented participants
September-December	Review Medical Records	Medical Researcher, Project Manager	- Review medical records for the past 5 years for approximately 2000 individuals that gave consent
December	Send 1 st draft of YKHEMP general results	ALL	- Send 1 st draft of general descriptive results for stakeholder feedback
JANUARY 2019			
January <i>(on-going)</i>	Data Analyses continues	uOttawa	- Lab analysis of toenail clippings from 2018 participants continues - In-depth analysis of data
February	Send individual results letters to ALL participants (2017 and 2018)	uOttawa, HEMPAC, GNWT HSS	- Personal letters are sent out to participants with explanation of their results - Nurse Practitioner in place to answer questions, conduct follow-up, if necessary
February	In-person HEMPAC meeting in Yellowknife	ALL	- All stakeholders meet to discuss general results, communications in Yellowknife
February	Communications	uOttawa, HEMPAC	- Prepare PSAs, update website, Facebook to promote public meetings
February	Community meetings	ALL	- Prepare presentations - Share general results with YK general, YKDFN and NSMA populations

JOB DESCRIPTION - Project Manager (uOttawa-based)

The Project Manager works closely with members of the Health Effects Monitoring Program (YKHEMP) team and other individuals/groups involved in the program, including:

- i) Principal Investigator (PI);
- ii) Doctoral and Masters students (Janet/Claudia/Raj);
- iii) Assistant Coordinator, Community Project Coordinator, Field Coordinator;
- iv) Communications and Engagement Departments of INAC;
- v) Institute for Circumpolar Health Research (ICHR);
- vi) Health Effects Monitoring Program Advisory Committee (HEMPAC) including Giant Mine Oversight Board, Indigenous and Northern Affairs Canada (INAC), Health Canada, Yellowknives Dene First Nation, North Slave Metis Alliance, City of Yellowknife, Government of Northwest Territories Departments of Health and Social Services and Environment; and
- vii) Local organizations in Yellowknife.

Other related groups that the Project Manager will work with include Research Assistants, Registered Nurses, Medical Researcher, Nurse Practitioners, Questionnaire Developer, Statistics Canada, Labs, and other.

Project Administration

- Manage all the administrative, logistical, financial, and communication aspects of the program.
- Participate in monthly advisory committee, and other meetings as necessary, and prepare minutes;
- Develop and finalize Research Plan and associated documents: consent forms, assent forms, questionnaires;
- Develop and manage program budget;
- Develop community engagement strategies and messages;
- Develop and maintain program website, and Facebook;
- Develop job descriptions, interview and hire local staff; prepare work contracts;
- Complete and renew yearly uOttawa Ethics, Aurora College Scientific Research License and Certificate of Ethics;
- Develop and maintain Guiding Principles document;
- Develop recruitment letters, community presentations;
- Conduct a pilot study in Yellowknife to test procedures, questionnaires;
- Prepare Training materials i.e. guidelines for data collection, sampling procedures, etc;
- Interview and hire up to 15 to 20 Research Assistants, 4 Nurses, 1 Medical Researcher;

- Train local staff;
- Purchase program supplies.

Contact and liaise project activities with Ndilo, Dettah and Yellowknife communities

- Travel to communities when appropriate, as a representative of the Health Effects Monitoring Program;
- Communicate regularly with, and coordinate program activities by working closely with the Assistant Coordinator based out of ICHR, and YKDFN Coordinator working out of YKDFN office;
- Attend stakeholder meetings as a representative of YKHEMP;
- Ensure consistency of communication with communities on the next steps such as:
 - i) Make public and increase visibility of the Health Effects Monitoring Program in the Yellowknife, Ndilo and Dettah;
 - ii) Coordinate sample collection;
 - iii) Recruit Research Assistants (RAs); Nurses; Medical Researcher;
 - iv) Organize the secure storage of supplies in Yellowknife, the completed questionnaires, urine, toenail, saliva samples and other data;
 - v) Coordinate / monitor the transport of all research supplies and data to and from communities and other destinations outside of the communities.

Fieldwork Support

- Prepare, organize and provide the training of RAs and nurses;
- Support RAs, nurses and Medical Researcher during the data collection periods;
- Manage staff salary and other expenses;
- Maintain regular communication with all staff to ensure that the program follows the agreed timelines and protocols;
- Prepare regular updates to the PI and HEMPAC;
- Maintain availability of travel, often with tight deadlines, to Ndilo, Dettah and Yellowknife communities, as needed.

Community Communication and Engagement

Working together with INAC's communication and engagement staff as well as the Giant Mine Oversight Board, the Project Manager will be responsible for developing the following materials and/or products: brochure, posters, program website, announcements on radio/newspapers, recruitment letters, community presentations, newsletters, and other materials, as necessary.

Shipping and Storage of Research Supplies

The Project Manager will arrange secure storage of research supplies, toenails, saliva, urine samples, and other data.

The Field Coordinator and Project Manager will coordinate and track the transportation of supplies, samples and data files to the University of Ottawa or Génome Quebec.

Reporting

The Project Manager will provide program updates on timeline of activities, community engagement, data collection, and other issues to the PI, GNWT project manager, INAC (funder) and HEMPAC, on a regular basis.

The Project Manager will compose agendas and participate in Advisory Committee meetings and provide updates on the monitoring program.

JOB DESCRIPTION – Assistant Coordinator (ICHR-based)

The Assistant Coordinator is based at the Institute for Circumpolar Health Research (ICHR) in Yellowknife. She will work closely with the Project Manager and be supported by the ICHR staff to help communicate, promote, and implement the monitoring program in Yellowknife. The Assistant Coordinator will also attend key events, answer questions from the public, help to implement and provide support to research assistants during data collection, and liaise with varied stakeholders while maintaining positive relationships.

Some of the responsibilities include but are not limited to:

- Represent the program & liaise with varied stakeholders in Yellowknife to promote the Health Effects Monitoring Program
- Attend public events as a representative of the Monitoring Program
- Help set up local community meetings
- Work closely with Project Manager at University of Ottawa & provide a weekly updates
- Attend monthly teleconference meetings & other meetings as necessary
- Assist in developing Medical Records access plan
- Assist in printing/distributing brochures, posters; advertising on local radio and newspapers
- Assist in organizing a pilot study
- Assist in hiring research assistants
- Assist principal investigator in organizing the return of research results to participants
- You may be asked to work some evenings especially during community meetings and data collection
- Provide other administrative and logistical support as needed

JOB DESCRIPTION – Community Project Coordinator (YKDFN-based)

The Yellowknives Dene First Nation (YKDFN)-based Community Project Coordinator for the Health Effects Monitoring Program will work full-time from September 2017 to March 2019, splitting their time between 2 main components:

Component 1: HEALTH EFFECTS MONITORING PROGRAM

- Expected commitment: Sept-Dec 2017 and Sept-Dec 2018

Component 2: YKDFN ARCHIVES

- Expected commitment: Jan-Aug 2018, Jan-Mar 2019

The Community Project Coordinator position will start September 2017 until March 31, 2018, with the expectation that their contract will be renewed on April 1st 2018 for a second fiscal year.

Roles and responsibilities:

Roles	Responsibilities
HEALTH EFFECTS MONITORING PROGRAM	<ul style="list-style-type: none"> - Participate in a 1-day Methodology Workshop in Yellowknife. - Participate in a 2-day training covering interviewing skills. - Provide logistical support for community meetings (e.g. room, translation). - Work closely with the YKDFN members and help set up appointments with the nurse including door to door and call-in sessions. - Provide awareness among community members <ul style="list-style-type: none"> ○ YKDFN Facebook page/news letter ○ Assist in door to door distribution of Invitation Letters to all households with help from local youth - Attend other events as necessary to share information about the program. - Be involved in communications about the monitoring program - Attend bi-weekly meetings with the research team (Renata, Stacey, Carine) via teleconference or in-person, to connect with the rest of the Health Effects Monitoring Program team during data collection as necessary (September-December). - Attend all monthly HEMPAC meetings. - Attend GMAC, and Giant Mine Working Group meetings as necessary.

Roles	Responsibilities
<p>YKDFN ARCHIVES:</p> <p>Review and analyze YKDFN archive files</p>	<ul style="list-style-type: none"> - Review and analyze sensitive YKDFN archive files. - Compile relevant information for review of the YKDFN executive. - Categorizing and organizing data into an accessible format. - Distribute or communicate information as necessary to the respective organizations and YKDFN members.

The Community Project Coordinator will report to William Lines under the authority of Chief and Council, and work closely with Renata Rosol (Program Manager), and Stacey Sundberg (Assistant Coordinator) during critical periods of the Health Effects Monitoring Program (e.g. training, data collection from September to December, and returning individual results to participants).

COMMUNICATIONS AND ENGAGEMENT PLAN Overview

(For more details refer to the Communications & Engagement Plan)

Community engagement is of utmost importance as this program will require the participation and engagement of the Greater Yellowknife population, the Yellowknives Dene First Nation and the North Slave Métis Alliance. Communication strategies will be implemented throughout the project. Communication will occur well before recruitment and commencement of the project to inform the community of the upcoming monitoring program.

A monitoring program of this scale and of this matter requires community engagement through constant community engagement and transparency. It is important to work closely with the concerned community and explain clearly the choices being made. It is understood that some community members may be reluctant to participate in certain parts of sampling or to divulge their medical history. The consent form will clearly state that the participant has the right to opt out of any portion of the project while still being able to participate in the rest of the project (e.g. refuse to give DNA sample but still give urine and toenail samples and fill out the questionnaire). This will ensure a better participation rate for the project as opposed to requiring participation in all components of the project.

The Giant Mine Project Team will finalize an Engagement and Communications Plan with input from uOttawa and HEMPAC members. Both Giant Mine Project Team and uOttawa will work together at developing, maintaining, planning and/or implementing different parts of the communication plan. The Plan outlines the following key objectives and methods to be used for the program:

Objectives

- Keep people/groups of interest informed on the goals, process, and results of the Health Effects Monitoring Program in a manner that is in plain, meaningful language using a variety of communication channels.
- Gain community perspective, expertise, and advice in developing, implementing, and communicating the Health Effects Monitoring Program.
- Identify and educate potential participants.
- Generate community interest, support and involvement for the Health Effects Monitoring Program.
- Ensure Ndilo, Dettah, and Yellowknife residents are:
 - aware that the study is occurring,
 - understand what the objectives and limitations of the study are (for example, the study cannot measure historic exposure),
 - know how they can participate,
 - know how participants are selected, and
 - inform participants throughout the process of the progress and results.
- Create an atmosphere of trust to encourage feedback and to have people/organizations feel that their contributions are validated.
- Allow for changes to the study design (prior to submitting for ethics approval) as a result of recommendations by the Health Effects Monitoring Program Advisory Committee.
- Ensure stakeholder groups have the opportunity to recommend the most effective venues to communicate information throughout the Program.
- Ensure selected participants are comfortable participating in the study. (safety, confidentiality, access to results)
- Address questions about impacts of arsenic in the environment on human health
- Address perceived health risks. Prevent misinformation from circulating and causing undue panic.
- Reinforce that the Giant Mine Remediation Project is operating in an open, inclusive, and transparent manner.
- Demonstrate how this study will directly address some of the concerns raised in the Environmental Assessment process.
- Provide a venue where questions can be answered.
- Ensure questions from media and community members are addressed in a timely manner where Giant Mine Remediation Project is the lead, and direct questions to the appropriate agencies where required.

Key Engagement Methods

uOttawa will take the lead on developing the following key products for the Monitoring Program. INAC will provide feedback and technical support to uOttawa as needed. Additional input will be sought from HEMPAC:

- Logo design
- Brochure (English / Wiliideh)
- Poster
- Website design
- Newsletters
- Media interviews
- Articles in local paper
- Recruitment letters
- Presentations
- Community meetings with Yellowknife general population, YKDFN and NSMA

INAC will manage/post information and updates related to the Monitoring Program on:

- Giant website (English/French)
- E-newsletter; Twitter
- Public forums

HEALTH EFFECTS MONITORING PROGRAM ADVISORY COMMITTEE (HEMPAC)

Monthly meetings

Advisory Committee meetings are held by conference call on the **second Friday of every month**. This meeting may be postponed if there are no updates to be presented.

The Program Coordinator drafts the agenda based on updates of current program activities, and sends out to GNWT and INAC for additional input. After input is provided the updated agenda is emailed to the Advisory Committee members. The Program Coordinator takes notes and initial draft is reviewed by the PI, GNWT and INAC before a final draft is sent to the Advisory Committee for changes, additions and deletions. Any changes will be incorporated into the project record.

Monthly invites will be sent through google calendar to all HEMPAC members. Any attachments will be sent through Email due to the presence of firewalls in some government departments.

Face to Face meetings usually occur one to two times a year. Dr. Chan will usually make the decision for a face to face Advisory Committee meeting.

Mandate of the Advisory Committee

To provide advice and make recommendations to the Principal Investigator in the development and implementation of the monitoring program by utilizing health expertise, and knowledge of regional and community level issues.

The HEMPAC will be chaired by the INAC representative. The INAC rep will provide a communication link between the HEMPAC, the Principal Investigator and the GMRP Team. The INAC rep will preside over the meetings, and coordinate activities of the HEMPAC. The Chair is a full member of the HEMPAC.

Specific responsibilities of the Advisory Committee include but are not limited to:

- Provide technical expertise and advice in the development and implementation of the Health Effects Monitoring Program.
- Provide community perspective, expertise, advice and traditional knowledge in the development and implementation of the monitoring program.
- Monitor the implementation of the program and provide input into refinement opportunities.
- Provide advice on proposed communications for the monitoring program.