



UC San Diego



THE INDIGENOUS FUTURES LAB (IFL) FIELD SCHOOL: ENHANCING ETHICAL GENOMIC RESEARCH WITH INDIGENOUS COMMUNITIES MO'OREA, FRENCH POLYNESIA

Course ID: TBA

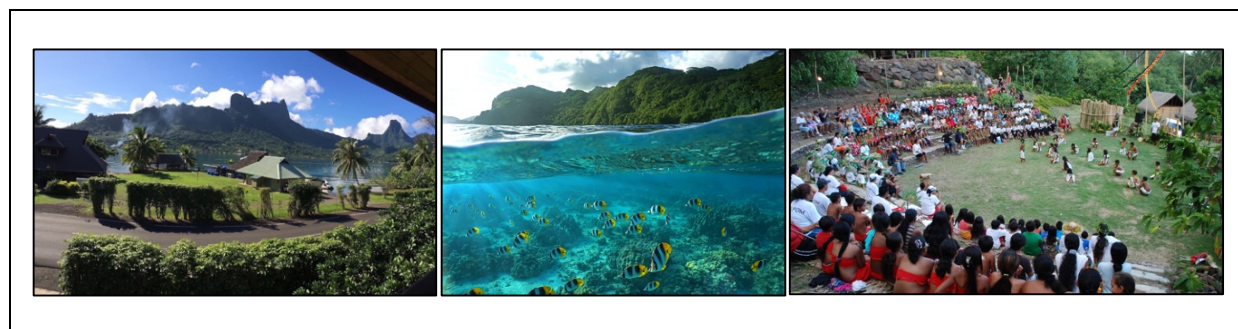
June 21-July 18, 2020

Academic Credits: 8 Semester Credit Units (Equivalent to 12 Quarter Units)

School of Record: Connecticut College

FIELD SCHOOL DIRECTOR:

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INTRODUCTION:

Currently eighty-eight percent of large scale screens of human genetic variation, and ninety-five percent of clinical trials, feature exclusively individuals of European ancestry. As a result, the future of biomedicine (i.e. personalized, predictive, and preventative medicine) does not include underrepresented minorities (including Indigenous peoples). This bias and systematic lack of engagement of underrepresented minorities/ Indigenous people in both clinical trials and genome studies is partially the result of a history of distrust. Through the Indigenous Futures Lab (IFL) Field School we will train the next-generation of global health professionals to imagine, promote, and sustain a future where Indigenous people are partners in, and not subjects of, genetic research.

SUMMARY

The IFL Field School is a medical anthropology/global health -based field school that utilizes community-based participatory research methods (CBPR). The purpose is to train student participants to engage Indigenous communities using culturally sustainable methods, and co-develop novel hypothesis related to Indigenous health. In partnership with the Moruroa e tatou association, the Atitia Center and the University of California Berkeley Gump Research Station (all located in Mo'orea, French Polynesia), we have established a field school lead by an interdisciplinary team of Indigenous/Pasifika scholars. Our goal is to recruit Polynesian community members as participants in a long-term study to identify the impact of colonialism on the human genome.

In Summer 2020 we will focus on two specific research questions:

Specific aim 1) European first contact: Our aim is to understand how the introduction of leprosy, smallpox, syphilis and other diseases from European colonialists in the eighteenth century have shaped the genomes of Indigenous Polynesians today. Specifically, we would like to discover which gene regions have been effected by this “selective sweep” (i.e. population bottleneck) and how this instance of first contact has predisposed Indigenous Polynesian peoples to immunological and inflammation related disease today.

Specific aim 2) Nuclear radiation exposure: Our aim is to understand the effect of nuclear testing (i.e. invisible pollution) in the Tuamotus islands from 1966–1996 and its role in cancer prevalence among individuals who were exposed to nuclear radiation and; generations of their descents who might develop cancer in the future (i.e. identify epigenetic or transgenerational effects as a result of nuclear radiation exposure). Currently there is a huge variance in estimates for the number of people suffering from thyroid, lymph node, and leukemia cancers in the French Polynesian population. We would like to use anthropological field work methods (e.g. ethnography and survey) within a public health epidemiology framework to address the paucity of information related to number of individuals suffering from nuclear radiation exposure based cancers.

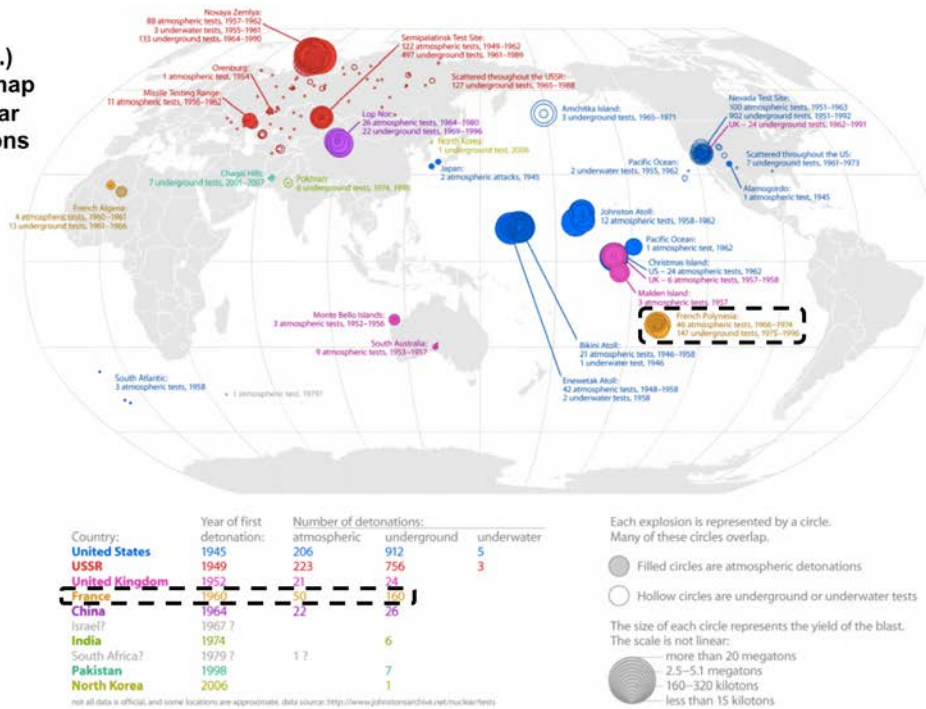
Connecting specific aims 1 & 2: Archaeological, linguistic, and genetic data support the theory that modern Polynesian populations have experienced multiple population bottle-necks resulting in a reduction in human genetic variation. This includes (1) a founder effect bottleneck as proto-Austronesian voyaging groups discovered island chains in the Pacific Ocean followed by (2) European contact, exposure to multiple disease epidemics, and a population collapse or reduction in eighty-percent of the total population by the end of the eighteenth century. We believe that identifying regions of the human genome that are under-selection (i.e. bottlenecked) will contribute to our understanding of cancer susceptibility in modern Polynesian populations today.

Field Sites: To accomplish this, we will establish two field sites in Mo’orea, Tahiti; The first will utilize the existing laboratory infrastructure at the UC Berkeley Gump station as a lab headquarters to store equipment and supplies (e.g. buccal swabs, DNA extraction kits, etc.). We will recruit Tahitian community members through the Moruroa e tatout Association and the Atitia Center (i.e. a community-based organization dedicated to documenting, promoting, and preserving Polynesia’s biocultural heritage) located next-door to the UC Berkeley Gump Research Station.

In our second field site, we will work with local clinicians through both the Moruroa e Tatou association and the Fare Ma’i Health center (Both located on Mo’orea). Through the Moruroa e tatou association we will work with former workers and soldiers who were exposed to nuclear radiation through French nuclear trials in French Polynesia (i.e. Moruroa and Fangataufa) since July 2nd, 1966 (the date of the first nuclear trial), their relatives and inhabitants of French Polynesia claiming to be the victims of the 193 nuclear trials performed between 1966-1996 (**See Figure 1**).

Technology on the go: Inclusivity, accessibility, & independence: One of the goals of our field school is to expose our students to mobile/portable methods to explore the potential to generate data in remote/ inaccessible locations. This includes connecting and collecting genotype and phenotype data. As a result, we will work with local clinicians at the Fare Ma’i Health center to create clinically relevant phenotype data for cancer (pre)screening (e.g. thyroid, lymph node, and leukemia cancers). Clinicians on our team will work with and train local clinicians to use point-of-care diagnostic tools including mobile ultrasound, mobile micro CT scanner, and cancer/immunology related blood cell panels. Finally, we hope that the IFL Field School can help Polynesian communities repatriate their deep-past, their identify today, and lead to the development of population-specific cancer treatment(s) in the future.

**Figure 1.)
Global map
of nuclear
explosions**



ACADEMIC CREDIT UNITS & TRANSCRIPTS

Credit Units: Attending students will be awarded 8 semester credit units (equivalent to 12 quarter credit units) through our academic partner, Connecticut College. Connecticut College is a private, highly ranked liberal arts institution with a deep commitment to undergraduate education. Students will receive a letter grade for attending this field school (see grading assessment and matrix). This field school provides a minimum of 160 direct instructional hours. Students are encouraged to discuss the transferability of credit units with faculty and registrars at their home institution prior to attending this field school.

Transcripts: An official copy of transcripts will be mailed to the permanent address listed by students on their online application. One more transcript may be sent to the student home institution at no cost. Additional transcripts may be ordered at any time through the National Student Clearinghouse: <http://bit.ly/2hvurkl>.

PREREQUISITES

There are no academic prerequisites for this field school. Furthermore, there are no expectations that students will have had any medical anthropology or global health training prior to the field school. At the same time, the field school will require students to come prepared with a growth mindset geared towards understanding a new culture. We will be working with community members who are generous enough to share their culture with our field team. In addition to obtaining IRB approval from the University of California system, the Indigenous Futures Lab Field School is also in the process of obtaining international accreditation/approval from the French Polynesian bioethics board with guidance from Philippe Temauiri'i Neuffer, Francois Pihaatae, and the Moruroa e tatou association. The weather will be tropical and hot and the time dedicated to fieldwork and interaction with new people from new cultures will be both mentally challenging and physically demanding. Students are required to come into this field school equipped with an understanding of the challenges of this field school, as well as an excitement to meet them.

DISCLAIMER – PLEASE READ CAREFULLY

Our primary concern is with education. Traveling and conducting field research involves risk. Students interested in participating in any IFR program must weigh whether the potential risk is worth the value of education provided. While risk is inherent in everything we do, we take risk seriously. The IFR engages in intensive review of each field school location prior to approval. Once a program is accepted, the IFR reviews each program annually to make sure it complies with all our standards and policies, including student safety.

This field school will take place in a tropical and hot environment. During the winter (US summer) temperatures in Mo'orea routinely break 90 degrees. The landscape also contains dangerous disease carrying insects (i.e. mosquitos that could potentially transmit dengue fever). Due to the dangers of this environment students will be expected to be attentive to the directions of field school staff at all times. Students are also expected to be respectful towards locals as well as towards their fellow students.

The IFR does not provide trip or travel cancellation insurance. We encourage students to explore such insurance on their own as it may be purchased at affordable prices. insuremytrip.com or Travelgurad.com are possible sites where field school participants may explore travel cancellation insurance quotes and policies. If you do purchase such insurance, make sure the policy covers the cost of both airfare and tuition. See this [Wall Street Journal article about travel insurance](#) that may help you with to help to decide whether to purchase such insurance

We do our best to follow schedule and activities as outlined in this syllabus. Yet local permitting agencies, political, environmental, personal or weather conditions may force changes. This syllabus, therefore, is only a general commitment. Students should allow flexibility and adaptability as research work is frequently subject to change.

If you have any medical concerns, please consult with your doctor. For all other concerns, please consult with the project directors.

COURSE OBJECTIVES

The IFL field school, focused on the study of human genetic variation in the Tahitian community, will train students in genetic epidemiology, community based participatory research (CBPR), and global/Indigenous health screening methods.

By prioritizing CBPR methods, we will train our student participants to engage Polynesian communities using culturally sustainable methods to co-develop novel hypothesis related to Indigenous health (*i.e.* engage Indigenous community members as partners, not subjects). Topics of interest include assessing Tahitian attitudes towards (i) genetic testing in Polynesia, (ii) the early migratory history of Polynesia, (iii) local histories/narratives around European first contact/disease exposure, and (iv) attitudes around colonialism and the impact of the French government testing 193 nuclear bombs in the Tuamotus islands from 1966-1996 (*i.e.* gene environment interaction and cancer susceptibility).

This course has five primary goals:

1. To provide students with hands on training in the techniques of community based participatory research (CBPR); this includes participatory action research and collaborative inquiry, and the iterative process of co-designing informed consent.

2. To train students in some of the basic techniques of oral history and ethnography. Specifically, methods will include participant observation, survey/questionnaire, local interviews with Tahitian residents, and recording of local histories.
3. To provide students with practical working knowledge of how these various methods can be used to answer anthropological research questions.
4. To familiarize students with the history of colonialism in French Polynesia, and a number of the anthropological and political issues that surround this history (e.g. European contact in the eighteenth century and nuclear testing from 1966-1996).
5. Finally, students will work with both our field team and local public health officers and Tahitian clinicians to learn DNA collection techniques and thyroid cancer screening and pre-screening techniques to generate phenotype data to empirically determine the rates/frequencies of thyroid, lymph node, and leukemia cancers in French Polynesia— connecting the environmental impact of nuclear radiation exposure to human health and longevity in Polynesia.

LEARNING OUTCOMES

By the end of the field school, students will:

- Be able to take detailed ethnographical field notes.
- Have experience in CBPR techniques, as well as co-design of informed consent.
- Learn the basics of ethnographic data collection including interviewing, audio recording, coding of audio and photographic data, and ethnographic note taking.
- Have experience collecting buccal swab DNA, isolating DNA, storing biological material, and cataloguing biological material.
- Learn the basics of clinical phenotype collection (i.e. height weight etc.), mobile/portable phenotype data collection (i.e. observing/shadowing), and data storage in remote/isolated locations.

GRADING MATRIX

- A. Daily participation in field activities including survey, excavation, administering interviews, notetaking, mapping, cleaning and analyzing artifacts (40% of grade).**
- B. Laboratory Work (10% of Grade):** Each week students will spend a day in the laboratory working on various tasks. This will include analyzing material culture and organizing databases used to store spatial data, photographic data, audio data, and any other information collected by the field school. Students will work closely with the lab staff to analyze and enter field school data. Students will be evaluated on their active participation in these activities including keeping a detailed journal of their tasks accomplished and skills learned
- C. Discussion of Readings and Field Activities (10% of Grade):** Each Monday, students will meet with instructors and TAs for a lecture/seminar to discuss the assigned readings. Two students each night will be assigned to lead group discussions. Students will be expected to read all assigned articles and write notes in their journals for each article. Students will be evaluated based on their oral comments made during group discussion, as well as written comments in their journals. Both written and oral comments should not merely summarize the readings but make a substantive comment that demonstrate critical analysis and engagement of these readings to the broader themes of the field school.
- D. Daily Field and Lab Journals (20%):** Students are expected to keep a detailed daily journal for four weeks on the different activities the students are involved with. Students should not just describe what they did, but what they are learning and how the activities they engage with are connected to the broader themes of the fieldwork and the theoretical themes raised in the readings and discussion.

- E. Independent Student Projects (20%):** Every student will design and carry out an individual research project during the four weeks of the field school.
- a. During the first week of the field school students will meet with instructors to discuss research interests and potential research topics. They will hand in a **single page research proposal** by the beginning of second week that lays out what they plan to do and how they plan to do it.
 - b. Throughout the four weeks of the field school students will carry out this research plan alongside their regular field school responsibilities. Students will meet with the TAs/instructors by the beginning of fourth week to make sure their project is on track.
 - c. **Final Presentation-** At the end of the last week students will give a 15 minute long PowerPoint presentation that describes their research question and how they answered it.

TRAVEL & MEETING POINT

We suggest you hold purchasing your airline ticket until six (6) weeks prior to departure date. Natural disasters, political changes, weather conditions and a range of other factors may require the cancelation of a field school. The IFR typically takes a close look at local conditions 6-7 weeks prior to program beginning and make Go/No Go decisions by then. Such time frame still allows the purchase deeply discounted airline tickets while protecting students from potential loss if airline ticket costs if we decide to cancel a program.

All students will fly into Pape'ete, Tahiti (PPE), and will be picked up at the airport by the instructors on Sunday, June 21, between 12 pm – 5 pm. From the airport they will be driven to the Ferry Terminal and transported to Mo'orea.

If you missed your connection or your flight is delayed, please call, text or email the project director immediately. A local emergency cell phone number will be provided to all enrolled students.

VISA REQUIREMENTS

As this field school will be in French Polynesia, there are no visa requirements for US citizens. However, students must bring their passports. Non-US Citizens are asked to check the embassy website page at their home country for specific visa requirements.

ACCOMMODATIONS

Students and instructors will stay in the UC Berkley Gump Station Dorms, a multipurpose facility and the Atitia community center located next to the UC Berkeley Gump Research Station. In this community center students will share unfurnished private rooms and should bring sleeping bags, camping mats, and mosquito nets.

Both the UC Gump research station and the Atitia Center have kitchen facilities and all meals will be cooked by committee with students and staff organizing a shared cooking schedule. Any allergies will be strictly monitored and dietary restrictions such as vegetarianism will be accommodated.

COURSE SCHEDULE

All IFR field school begins with safety orientation. This orientation includes proper behavior at the field area, proper clothing, local cultural sensitivities and sensibilities, potential fauna and flora hazards, review IFR harassment and discrimination policies and review of the student Code of Conduct.

| Week | Date | Day of the Week | Activity | Lecture | Readings |
|------|---------|-----------------|--|--|--|
| 1 | June 21 | Sunday | Student Arrival and Travel to Gump Station. Welcome Dinner | | |
| 1 | June 22 | Monday | Research/ Safety Orientation: Gump Station and lab facilities. | Welcome from the community: Indigenous Futures Lab and introduction to “colonialism in Polynesia” | Selections from <i>Decolonizing methodologies</i> Carlos Bustamante et al. , “Genomics for the world” Keolu Fox & John Hawks , “Use ancient remains more wisely” |
| 1 | June 23 | Tuesday | Research/Safety Orientation: Atitia Center Site Visit | From Cook to Cortes: History of European First Contact In Polynesia | Selections from <i>Aphrodite’s Island: The European Discovery of Tahiti</i> Selections from <i>Sea People: The Puzzle of Polynesia</i> |
| 1 | June 24 | Wednesday | Ethnographical Survey and CBPR Practicum in Mo’orea/ Tahiti | CBPR: Methods for culturally sustainable research Responsible Genetic Research With Vulnerable Populations. | Selections from <i>Review of community-based research: assessing partnership approaches to improve public health.</i> Katrina Claw , “A framework for enhancing ethical genomic research with Indigenous communities” Swapan Mallick , “The Simons Genome Diversity Project: 300 genomes from 142 diverse populations” |
| 1 | June 25 | Thursday | Field Work: Gump—Survey Atitia—Getting acquainted with locals | | |
| 1 | June 26 | Friday | Field Work: Gump—Survey | | |

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| | | | Atitia—Getting acquainted | | |
| 1 | June 27 | Saturday | Field Work: Gump—Survey Atitia—Getting acquainted | | |
| 2 | June 28 | Sunday | Day Off (Field Trip to Opunopu Valley Archeological Site) + Snorkeling | | |
| 2 | June 29 | Monday | Field Work: Gump—Survey Atitia—Interviews and DNA collection | Ethnographic Interview and Oral Histories Research partners, not subjects: Consent & co-design | Micaela Di Leonardo, <i>“Oral History as Ethnographic Encounter”</i> Mike Allen, <i>“Ethnographic Interview”</i> Latifa Jackson et al., <i>“Including Vulnerable Populations in the Assessment of Data From Vulnerable Populations”</i> |
| 2 | June 230 | Tuesday | Field Work: Gump—Survey Atitia—Interviews and DNA collection | | |
| 2 | July 1 | Wednesday | Field Work: Gump—Survey Atitia—Interviews and DNA collection | | |
| 2 | July 2 | Thursday | Field Work: Gump—Survey Atitia—Interviews and DNA collection | | |
| 2 | July 3 | Friday | Field Work: Gump—Survey Atitia—Interviews and DNA collection | | |
| 2 | July 4 | Saturday | Field Trip Street Market: Pape’ete, Tahiti | | |

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| | | | Visit to Moruroa e tatou HQ | | |
| 3 | July 5 | Sunday | Day Off | | |
| 3 | July 6 | Monday | Field Work: Gump—Survey Fare Ma’i Health center —Getting acquainted | Technology on the go: Mobile Diagnostics for Human Biology Epigenetics in the shadow of the atom bomb | Peter Hackawill, <i>“Health consequences of nuclear tests in French Polynesia”</i> Caroline Free, <i>“The Effectiveness of Mobile-Health Technologies to Improve Health Care Service Delivery Processes: A Systematic Review and Meta-Analysis”</i> Ariana Eunjung Cha, <i>“The Human Upgrade: The Revolution will be digitized”</i> |
| 3 | July 7 | Tuesday | Field Work: Gump—Survey Fare Ma’i Health center— Getting acquainted | | |
| 3 | July 8 | Wednesday | Field Work: Gump—Survey Fare Ma’i Health center— Interviews and DNA collection | | |
| 3 | July 9 | Thursday | Field Work: Gump—Survey Fare Ma’i Health center— Interviews and DNA collection | | |
| 3 | July 10 | Friday | Field Work: Gump—Survey Fare Ma’i Health center— Interviews and DNA collection | | |
| 3 | July 11 | Saturday | Field Work: Gump—Survey Fare Ma’i Health center— | | |

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|---|---------|-----------|--|---|--|
| | | | Interviews and DNA collection | | |
| 3 | July 12 | Sunday | Day Off | | |
| 4 | July 13 | Monday | Field Work: Gump—Survey Fare Ma’i Health center— Interviews and DNA collection | Epigenetics and transgenerational modifications | C. David Allis et al., <i>“The molecular hallmarks of epigenetic control”</i> Benedict Carey, <i>“Can we really inherit trauma?”</i> R. Yehuda, <i>“Intergenerational transmission of trauma effects: putative role of epigenetic mechanisms”</i> |
| 4 | July 14 | Tuesday | Field Work: Gump—Survey Fare Ma’i Health center— Interviews and DNA collection | | |
| 4 | July 15 | Wednesday | Field Work: Gump—Survey Fare Ma’i Health center— Interviews and DNA collection | | |
| 4 | July 16 | Thursday | Last Field Day | | |
| 4 | July 17 | Friday | Independent Project Work day | | |
| 4 | July 18 | Saturday | Students Leave | | |

EQUIPMENT LIST

Required:

- Mosquito net
- Mosquito spray
- Camping sleeping mat or inflatable mattress (there are options to buy on island).
- Sleeping bag
- Pillow
- Sunscreen
- Wide Brimmed hat
- Sunglasses
- 2 Water bottles
- Pens/Pencils
- Sharpie
- Gloves
- Backpack
- Flashlight

Recommended:

- Fins

- Mask + Snorkel
- Swimsuit / board shorts
- Rash-guard
- Recommended Field Clothes: Long pants, long breathable shirts, hiking shoes.

REQUIRED READINGS

PDF files of all mandatory readings will be provided to enrolled students via a shared Dropbox folder.

Allis, C.D. & Jenuwein, T., 2016. The molecular hallmarks of epigenetic control. *Nature reviews. Genetics*, 17(8), pp.487–500.

Bustamante, C.D., Burchard, E.G. & la Vega, De, F.M., 2011. Genomics for the world. *Nature*, 475(7355), pp.163–165.

Claw, K.G. et al., 2018. A framework for enhancing ethical genomic research with Indigenous communities. *Nature communications*, 9(1), p.2957.

Di Leonardo M. et al., 1987. Oral history as ethnographic encounter. *JSTOR. The Oral History Review*.

Fox, K. & Hawks, J., 2019. Use ancient remains more wisely. *Nature*, 572(7771), pp.581–583.

Free, C. et al., 2013. The Effectiveness of Mobile-Health Technologies to Improve Health Care Service Delivery Processes: A Systematic Review and Meta-Analysis T. Cornford, ed. *PLOS Medicine*, 10(1), p.e1001363.

Hakewill, P., Dallemagne, G. & Holdstock, D., 1995. Health consequences of nuclear tests in French Polynesia. *The Lancet*, 346(8974), p.576.

Howitt, P. et al., 2012. Technologies for global health. *The Lancet*, 380(9840), pp.507–535.

Israel, B.A. et al., 2003. REVIEW OF COMMUNITY-BASED RESEARCH: Assessing Partnership Approaches to Improve Public Health. *doi.org*, 19(1), pp.173–202.

Jackson, L. et al., 2019. Including Vulnerable Populations in the Assessment of Data From Vulnerable Populations. *Frontiers in Big Data*, 2, p.68.

Jamison, D.T. et al., 2013. Global health 2035: a world converging within a generation. *The Lancet*, 382(9908), pp.1898–1955.

Mallick, S. et al., 2016. The Simons Genome Diversity Project: 300 genomes from 142 diverse populations. *Nature*, 538(7624), pp.201–206.

Morgan, H.D. et al., 1999. Epigenetic inheritance at the agouti locus in the mouse. *Nature genetics*, 23(3), pp.314–318.

Smith, L.T., 2013. *Decolonizing Methodologies*, Zed Books Ltd.

Tahiti, A.S.T.E.D.O.2010, Aphrodite's island. *academia.edu*

Technology, M.L.L.L.2007, Culture, culture learning and new technologies: Towards a pedagogical framework. *scholarspace.manoa.hawaii.edu*

Wander, M., 2018. Artefacts of Encounter: Cook's Voyages, Colonial Collecting and Museum Histories ed. by Nicholas Thomas et al. *The Contemporary Pacific*, 30(1), pp.236–238.

Yehuda, R. & Lehrner, A., 2018. Intergenerational transmission of trauma effects: putative role of epigenetic mechanisms. *World Psychiatry*, 17(3), pp.243–257.

RECOMMENDED READINGS

- Bardill, J. et al., 2018. Advancing the ethics of paleogenomics. *Science (New York, N.Y.)*, 360(6387), pp.384–385.
- Casper, S., 2011. The Collectors of Lost Souls: Turning Kuru Scientists into Whitemen by Warwick Anderson The Social Construction of Disease: From Scrapie to Prion by Kiheung Kim. *Journal of the History of the Neurosciences*, 20(2), pp.160–166.
- Crowe, 2018. Pathway of the Birds: The Voyaging Achievements of Māori and Their Polynesian Ancestors.
- de Vries, P. & Seur, H., 2001. Moruroa and Us: Polynesians' experience during thirty years of nuclear testing in the French Pacific. *Prime : journal of the International Peace Research Institute Meiji Gakuin University Tokyo*, 14, pp.2–18.
- Finney, B.R., 1977. Voyaging canoes and the settlement of Polynesia. *Science (New York, N.Y.)*, 196(4296), pp.1277–1285.
- Kirch, P.V., 2017. *On the road of the winds: an archaeological history of the Pacific Islands before European contact*.
- Markula, P., 2016. As A Tourist In Tahiti: An Analysis of Personal Experience. *Journal of Contemporary Ethnography*, 26(2), pp.202–224.
- Murray-McIntosh, R.P. et al., 1998. Testing migration patterns and estimating founding population size in Polynesia by using human mtDNA sequences. *Proceedings of the National Academy of Sciences*, 95(15), pp.9047–9052.
- Reardon, J., 2017. *The postgenomic condition: Ethics, justice, and knowledge after the genome*,
- Rothstein, M.A., Cai, Y. & Marchant, G.E., 2009. *The ghost in our genes: legal and ethical implications of epigenetics*, NIH Public Access.
- Shah, S., 2012. *The Body Hunters: Testing new drugs on the world's poorest patients*.
- Skoglund, P. et al., 2016. Genomic insights into the peopling of the Southwest Pacific. *Nature*, 538(7626), pp.510–513.
- Tayman, 2010. *The Colony. The Harrowing True Story of the Exiles of Molokai*.