

Legal, Ethical, & Social Issues in Public Health Genetics

PHG 512 | BH 514 | LAW H504 | GCNSL 512 (3 credits)
Autumn 2021 | Tues/Thurs 1:30-2:50 pm Pacific Time
Health Sciences Center **T360 (room updated 10/5)**

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Course Information

Contact Information

- Instructor: Sarah Nelson, MPH, PhD
- Pronouns: she/her/hers
- Office Hours:
 - Thursdays 3-4pm Pacific Time, PHG suite H-wing (H690)
 - virtual, by appointment
- Office Telephone: 206-543-1850
- E-mail: sarahcn@uw.edu (*preferred contact)
- Canvas course page: https://bit.ly/phg512_au21

Land Acknowledgement

The University of Washington acknowledges the Coast Salish people of this land, the land which touches the shared waters of all tribes and bands within the Duwamish, Suquamish, Tulalip and Muckleshoot nations.

COVID-related Expectations

Per UW policy, this class will be conducted in-person. Therefore, unless you meet the criteria for an accommodation from Disability Resources for Students (DRS) or a special arrangement approved by the SPH Office of the Dean that allows you to take the course remotely [\[see student communications here\]](#) you should only register for this class if you can attend in-person.

- Please contact UW Disability Resources for Students (DRS) directly if you feel you may be eligible for an accommodation based on your status as an immunocompromised individual or based on other diagnosed physical or mental health conditions that might prevent you from being able to take classes in-person.
- If you are a student enrolled in a program in SPH, and you are either living with an individual who is immunocompromised, OR you are unable to obtain a visa to travel to the US, you may be eligible for a “special arrangement” that will allow you to take this course remotely. Requests for special arrangements to take the class remotely should have been submitted to and approved by the Students and Academic Services team in the Office of the Dean before the beginning of the quarter. If you have questions about this type of arrangement, please reach out to Student and Academic Services by email at sphas@uw.edu.

All UW students are expected to complete their [vaccine attestation](#) before arriving on campus and to follow the campus-wide face-covering policy at all times. We are all expected to follow

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[state](#), [local](#), and [UW COVID-19 policies and recommendations](#). **If you feel ill or exhibit possible COVID symptoms, you should not come to class.** If you need to temporarily quarantine or isolate per CDC guidance and/or [campus policy](#), you are responsible for notifying your instructors as soon as possible by email. **If you receive a positive COVID-19 test result, you must report to campus Environmental Health & Safety (EH&S) by emailing covidehc@uw.edu or calling 206-626-3344.** Please see below for additional [contingency planning](#) for this course.

Food is not allowed in the classroom. Drinks may be sipped with lifting or removal of your facemask for a brief moment, and immediate re-masking after drinking.

Please check your email daily BEFORE coming to class. If we need to conduct class remotely because the instructor or a guest speaker is complying with UW policies and unable to attend in person, the instructor will send all registered students an email with a Zoom link for remote instruction. Thank you for your patience and support as we all transition together back to in-person learning!

Additional course format information

Modes of instruction

You will see the following terms used in the syllabus and on the Canvas website:

- **Synchronous instruction** refers to instruction that is live and delivered real-time, i.e. during the class scheduled meeting time.
 - ***In-person:*** The speaker/instructor is in the classroom.
 - ***Virtual:*** The speaker is attending remotely, via Zoom.
- **Asynchronous instruction** refers to instruction that is pre-recorded and made available online.

Lecture content will primarily be in-person synchronous but will also include virtual synchronous and asynchronous, depending on speaker availability, location, and format of their presentation. Any synchronous lecture content will also be recorded and posted to the Canvas website (please see [UW Privacy Office Statement below](#)). Discussion sessions will necessarily be synchronous. The course schedule on Canvas will be kept up to date and denote synchronous versus asynchronous instruction.

Remote alternative

- 1) Synchronous lectures are recorded and made available on the Canvas course site for asynchronous viewing after class.
- 2) An online discussion board is used for students to share reflections and questions on readings in advance of class sessions.

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- 3) The Canvas site is kept up-to-date with readings, lectures, assignments, and other class activities.

Technology

- Canvas - <https://itconnect.uw.edu/learn/tools/canvas/>
 - The course website will be a hub for class content, schedule, and discussion.
 - Canvas help for students:
<https://itconnect.uw.edu/learn/tools/canvas/canvas-help-for-students/>
- Zoom - <https://itconnect.uw.edu/connect/phones/conferencing/zoom-video-conferencing/>
 - UW provides a free Zoom Pro account to all UW students, faculty, and staff.
 - UW IT requires version 5.7.4 or higher
- Panopto - <https://itconnect.uw.edu/learn/tools/panopto/>
 - Synchronous, in-person lectures will be recorded with Panopto lecture capture technology and made available on the Canvas course site.

Guest speakers

To benefit from diverse perspectives and disciplinary backgrounds, several modules are delivered by guest speakers, including alumni of the Public Health Genetics graduate degree programs. Several scenarios are possible:

- Guest speakers who are currently part of the UW community may attend class in-person
- Other local guest speakers will likely deliver content virtually
- Non-local guest speakers will necessarily deliver content virtually

Contingency planning

In addition to [state](#), [local](#), and [UW COVID-19 policies and recommendations](#), below I offer additional contingency planning for different scenarios:

- If I cannot attend class in person due to illness, exposure, or possible symptoms:
 - I will notify the class as soon as possible, via Canvas announcements
 - If I am well enough, we will hold class fully remotely, via Zoom
 - If I am not well enough and there is not sufficient time to identify a substitute speaker, I will provide an alternative assignment or reading(s) via the Canvas site
- If a student cannot attend class in person due to illness, exposure, or possible symptoms (separate from approved accommodation requests for ongoing, fully remote attendance):
 - Please notify me via email as soon as possible and do not come to class
 - If you are well enough, engage with the course material via the [Remote alternative](#) described above until you are able to return in-person
 - Please communicate with me as far in advance as possible about any difficulties making due dates or inability to engage via the [Remote alternative](#)
- If we need to pivot to 100% remote instruction (i.e. at the University level)
 - We will utilize Zoom for synchronous class sessions, including lecture and breakout discussion groups.

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- Further adjustments will be decided and communicated as needed, in accordance with current University and SPH policies.

Course Description

This core course offered by the Institute for Public Health Genetics provides an introduction to the ethical, legal, social, and policy issues arising as genetic or genomic knowledge and technologies are developed and made available to individuals and populations. Students will learn to identify and anticipate potential ethical, legal, social, financial, and policy considerations that arise with emerging technologies when applied in clinical, research, consumer, and public health contexts. In this course, we will examine public health genetics issues from diverse disciplinary perspectives.

Course Objectives

By the end of the course, students will be able to:

1. Learn and apply different ethical, legal, social, and policy frameworks to key issues arising from historical and contemporary applications of genomic knowledge and technologies in public health.
2. Recognize, explore, and critique key issues in public health genetics through an ELSI (Ethical, Legal, and Social Implications) lens.
3. Debate key issues in public health genetics by taking a position on a controversial topic, identifying stakeholders, and arguing pros and cons from different stakeholder positions.
4. Critically analyze readings and issues and express positions in writing and discussion.

Council for Education of Public Health (CEPH) Competencies

1. Apply a public health policy framework to evaluate policy options in applications of genomic knowledge and technologies for disease prevention, screening, diagnosis, and/or treatment.
2. Apply an ethics framework to evaluate ethical implications of applications of genomic knowledge and technologies for disease prevention, screening, diagnosis, and/or treatment.
3. Investigate the ethical, financial, legal, social, and policy implications of current applications of genomic knowledge and technologies in public health.

ACGC Standards

For UW GCGP students, the following ACGC Standards are addressed in this course:

- A. ACGC Standards in content areas of:
 - a. Social, Ethical and Legal Issues in Genetics (B2.3.5)
 - i. genetic discrimination and related legislation

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- ii. health disparities
- b. Health Care Delivery Systems and Principles of Public Health (B2.3.6)
 - i. health and social policy
 - ii. financial/reimbursement issues
 - iii. population-based screening-newborn screening and carrier screening
 - iv. genetics as a component of public health services
- B. ACGC Practice-Based Competencies in *Domain I: Genetics Expertise and Analysis*
 - a. I.2a. Integrate knowledge of psychosocial aspects of conditions with a genetic component to promote client well-being.

Prerequisite/Corequisites

Introductory genetics or genomics education, training, or experience.

Textbook & Course Materials

There is no textbook for this course. All course materials, including required and optional readings, will be made available on the course Canvas website.

Course Schedule

Please refer to the Canvas course site for details on required reading and preparation for each class session. Instructor is Sarah Nelson and expected format is in-person synchronous unless noted otherwise.

Week One

Thursday 9/30/21

Course overview and introduction to Public Health Genetics and ELSI

Week Two

Tuesday 10/5/21

Introduction to ethics frameworks

Tuesday 10/7/21

Ethical issues in genetic research

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Week Three

Tuesday 10/12/21

Legal Overview

Guest lecturer: Anna Mastroianni, JD, MPH

Asynchronous lecture, in-class exercises

Thursday 10/14/21

Legal Overview, cont.

Guest lecturer: Anna Mastroianni, JD, MPH

Asynchronous lecture, in-class exercises

Week Four

Tuesday 10/19/21

Introduction to policy frameworks and analysis

Thursday 10/21/21

Genomics and Indigenous communities

Guest lecturer: Joseph Yracheta, MS, DrPH candidate

Week Five

Tuesday 10/26/21

Overview of Newborn Screening

Guest lecturer: Carmen Ng, MPH (IPHG alum)

Thursday 10/28/21

Policy Development in Newborn Screening

Guest lecturer: John Thompson, [fill in degree] (IPHG alum)

Week Six

Tuesday 11/2/21

Eugenics

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Thursday 11/4/21

Introduction to race, genetics, and ancestry
Guest lecturer: Malia Fullerton, DPhil

Week Seven

Tuesday 11/9/21

Race, ancestry, and genomic research

Thursday 11/11/21

No class - Veterans Day

Week Eight

Tuesday 11/16/21

Race, ancestry, and genomic medicine

Thursday 11/18/21

Consumer genetics

Week Nine

Tuesday 11/23/21

ELSI in Genetic Counseling (panel discussion)

Thursday 11/25/21

No class - Thanksgiving Day

Week Ten

Tuesday 11/30/21

Genetic surveillance of SARS-CoV2
Guest lecturer: Katherine Xue, PhD

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Thursday 12/2/21

ELSI of Polygenic Risk Scores

Week Eleven

Tuesday 12/7/21

Final student presentations

Thursday 12/9/21

Final student presentations

Grading Policy

Student responsibilities

Preparation and active participation are expected and essential to successful student learning in this course. Prior to each class session, students should carefully complete all required readings and viewings (including any required asynchronous, recorded content). Optional readings and exploration (e.g., additional articles, podcasts, videos) are not required but are instead offered as further exploration. It is the student's responsibility to communicate with the instructor about any extended absences or other extenuating circumstances that affect the student's ability to participate and complete assignments on time. Such circumstances will be negotiated on a case by case basis.

Graded Course Activities

Your course grade will be based upon the following activities (out of 200 points):

1. **Discussion questions** - 22.5% (45 points)

Prior to each class session:

- Develop one **discussion question** based on the required or optional readings and viewings and *post it to the Canvas discussion board* by 9 pm Pacific Time on the *day before the class session*.
- Be prepared to share your question(s) with the class and/or guest speaker.

Posting a discussion question on time for **15 class sessions** will earn you full credit, at 3 points per posting. Discussion questions posted after the cutoff earn 1 point. Responding to other

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students' posted questions, either before or following class, is encouraged but not required and not part of the participation grade. You are also welcome to submit more than one question but again this is not required and not part of the participation grade.

There are a total of 17 class sessions with required reading and preparation—each session except the two days of final presentations, December 7th and 9th—meaning you can **choose any 2 class sessions to not post a discussion question** and still earn full credit for discussion questions. You do not need to choose these 2 sessions in advance.

Graded activities 2-4 will be based on a topic related to the application of genomics knowledge and technologies in public health. Students will choose a topic early in the quarter and carry it forward through each of these assignments.

2. **Ethics analysis outline** - 20% (40 points), due October 29th

For this assignment, you will write an **outline of ethical analysis** on your chosen topic.

- Identify the ethical issues raised by the topic, including what is at stake. (10 points)
 - Include sufficient background information on the topic to describe the ethical issue.
- Select and briefly describe an **ethics framework** (e.g., bioethics principle-based, consequence-based, virtue-based). (10 points)
- Apply the selected ethics framework to discuss and reason through the ethical issues you have identified. (10 points)
- Identify a tension created by the use of your chosen framework. (10 points)
 - This could be a tension inherent in the given framework (e.g., a tradeoff between autonomy and beneficence in a principle-based framework) or an important moral consideration that is overlooked by using the framework (e.g., a consequence-based framework fails to consider virtue-based consideration of core roles and values).

3. **Final paper** - 35% (70 points), due December 3rd

The final paper for this class comprises a full write-up of your ethical analysis from assignment 2 above and a policy analysis. The sections of this paper are thus:

- (1) **Background section** introducing the topic and providing sufficient context to understand both the ethical issue and the policy problem. Identify who is affected and with what consequences (10 points)
- (2) A fleshed out write-up of your **ethics analysis outline** from assignment 2 above (20 points)
- (3) Propose a policy solution for your given topic by applying a **public health policy framework** to your chosen topic:
 - Stakeholder identification: Identify and describe at least two potential stakeholder groups (5 points per stakeholder group)

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- Policy analysis: Suggest a policy solution. Ground your suggested policy solution in your ethical analysis. (10 points)
- Stakeholder positions: For each stakeholder group, articulate pro and con positions for your suggested policy solution (5 points per stakeholder group)

Your final paper should be 4-8 pages, not including references (3 points for adhering to page limits). Minimum of 5 peer-reviewed references required (2 points). An additional 5 points are awarded for style and clarity of writing.

4. **Lightning talk** - 15% (30 points), presented in-class December 7th and 9th
Effectively and efficiently communicating complex topics to non-specialist audiences is an important part of public health genetics scholarship and practice. In this assignment, you will prepare a short oral presentation and slide show based on your topic for the quarter.

1. (Optional) Max 1 slide for background information
2. Summarize your ethical analysis (1-2 slides, 9 points)
3. Present your proposed policy solution (1-2 slides, 9 points)
4. Identify a future direction for ELSI research (conceptual or empirical) on this topic (1 slide, 9 points)

Presentations should be no longer than 5 minutes (3 points for presentation length).

5. **Self evaluation** - 7.5% (15 points), due December 16th
At the completion of the course, write a 1-page reflective statement on what you have learned during the course. Reflect on what surprised you, what you learned from yourself and your classmates, and what topics have particularly piqued your interest to learn more.

All assignments will be submitted via the course website on Canvas.

Late Work Policy

Late writing assignments and/or papers will be penalized 5% per day late (including weekends). *If you anticipate difficulty meeting an assignment due date, please reach out to the instructor as early as possible to discuss arrangements.*

Extra Credit Opportunities

Public health genetics and ELSI issues are discussed in many venues, including academic lectures or webinars, media articles, and podcasts. Watch a lecture or webinar (live or pre-recorded), read a media article, or listen to a podcast that is relevant to course content and write a half- to full page reflection. In your reflection, articulate the relevance to course content, describe at least one thing you learned, and identify at least one question that was raised for you (e.g., something you want to learn more about, or a potential research question/area of

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inquiry that you identified). Provide a link to the event, article, or podcast you are describing. Your selection can NOT be a required or optional material for this course. Students may submit one reflection for 5 points. Due December 16th.

Important Policies & Resources

Academic Integrity

Students at the University of Washington (UW) are expected to maintain the highest standards of academic conduct, professional honesty, and personal integrity.

The UW School of Public Health (SPH) is committed to upholding standards of academic integrity consistent with the academic and professional communities of which it is a part. Plagiarism, cheating, and other misconduct are serious violations of the University of Washington Student Conduct Code ([WAC 478-120](#)). We expect you to know and follow the university's policies on cheating and plagiarism, and the [SPH Academic Integrity Policy](#). Any suspected cases of academic misconduct will be handled according to University of Washington regulations. For more information, see the University of Washington [Community Standards and Student Conduct](#).

Access and Accommodations

Your experience in this class is important to me. It is the policy and practice of the University of Washington to create inclusive and accessible learning environments consistent with federal and state law. If you have already established accommodations with Disability Resources for Students (DRS), please activate your accommodations via myDRS so we can discuss how they will be implemented in this course.

If you have not yet established services through DRS, but have a temporary health condition or permanent disability that requires accommodations (conditions include but not limited to; mental health, attention-related, learning, vision, hearing, physical or health impacts), contact DRS directly to set up an Access Plan. DRS facilitates the interactive process that establishes reasonable accommodations. Contact DRS at disability.uw.edu.

Religious Accommodations

Washington state law requires that UW develop a policy for accommodation of student absences or significant hardship due to reasons of faith or conscience, or for organized religious activities. The UW's policy, including more information about how to request an accommodation, is available at [Religious Accommodations Policy](https://registrar.washington.edu/staffandfaculty/religious-accommodations-policy/) (<https://registrar.washington.edu/staffandfaculty/religious-accommodations-policy/>).

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Accommodations must be requested within the first two weeks of this course using the [Religious Accommodations Request form](https://registrar.washington.edu/students/religious-accommodations-request/) (<https://registrar.washington.edu/students/religious-accommodations-request/>).

Inclusion & Diversity

Diverse backgrounds, embodiments and experiences are essential to the critical thinking endeavor at the heart of University education. In SPH, we are expected:

1. To respect individual differences, which may include, but are not limited to, age, cultural background, disability, ethnicity, family status, gender, immigration status, national origin, race, religion, sex, sexual orientation, socioeconomic status and veteran status.
2. To engage respectfully in the discussion of diverse worldviews and ideologies embedded in course readings, presentations and artifacts, including those course materials that are at odds with personal beliefs and values.
3. To encourage students with concerns about classroom climate to talk to their instructor, adviser, a member of the departmental or [SPH EDI Committee](#), the Assistant Dean for EDI, or the program's director.

Classroom Climate

We Are a Learning Community. The development of a supportive learning environment is fundamental to this course and to productive interdisciplinary discussion. As a learner-centered classroom, we all have wisdom and experience to share. Students and the instructors are expected to share their knowledge, comments, critiques, feedback and alternate opinions. Our learning space is the mutual responsibility of the instructors and the students; as such, we have a responsibility to engage in dialogue in a way that supports learning for all of us. The co-creation of this respectful environment will be fostered by listening to views other than your own with an open mind, being able to understand and appreciate another person's point of view and the ability to articulate your own point of view using direct communication. Being conscious of not monopolizing dialogue and/or interrupting will help create this environment as well. vg@uw.edu is a resource for students with classroom climate concerns.

We have the privilege of learning together and we have a responsibility to engage in dialogue in a way that supports learning for all of us. Here are some practices we as learning community members can strive to use in our learning process (*to be discussed and refined during the first class session*):

- My own viewpoint is important—share it. It will enrich others.
- My students' and colleagues' viewpoints are important—listen to them. Do not judge them.
- Extend the same listening respect to others I would wish them to extend to me. We all have room to grow to become better listeners in non-judgmental ways.
- Recognize that I might miss things others see and see things others might miss.
- Raise my views in such a way that I encourage others to raise theirs.

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- Inquire into others' views while inviting them to inquire into mine.
- Ask questions when I don't understand something.
- Surface my feelings in such a way that we make it easier for others to surface theirs.
- Test my assumptions about how and why people say or do things.
- Challenge what was said or done, rather than make assumptions about the individual.
- Beware of either-or thinking.
- Be willing to take risks in moving outside my comfort zones.
- Affirm others.

Pronouns

We share our pronouns because we strive to cultivate an inclusive environment where people of all genders feel safe and respected. We cannot assume we know someone's gender just by looking at them. So we invite everyone to share their pronouns.

Bias Concerns

The SPH Office of the Dean has a [student concern policy](#), a faculty concern policy and standard HR procedures for staff concerns. Our 2018 climate survey states that most people in SPH do not report bias incidents because they do not know where to go. Students are encouraged to report any incidents of bias to someone they feel comfortable with, including instructors, advisers or department staff. They can email dcinfo@uw.edu for immediate follow up. Bias concerns can be anonymously and confidentially reported at this link <https://sph.washington.edu/about/diversity/bias-concerns>. Data is collected by the Assistant Dean for EDI and the Director of Program Operations for Student and Academic Services and tracked for resolution and areas are identified for further training.

Sexual Harassment

Sexual harassment is a form of harassment based on the recipient's sex that is characterized by:

1. Unwelcome sexual advances, requests for sexual favors, or other verbal or physical conduct of a sexual nature by a person who has authority over the recipient when:
 - Submission to such conduct is an implicit or explicit condition of the individual's employment, academic status, or ability to use University facilities and services, or
 - Submission to or rejection of the conduct affects tangible aspects of the individual's employment, academic status, or use of University facilities.
2. Unwelcome and unsolicited language or conduct that creates an intimidating, hostile, or offensive working or learning environment, or has the purpose or effect of unreasonably interfering with an individual's academic or work performance.

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If you believe that you are being harassed, or have observed harassment, you can report it to SPH using the [bias concerns link](#). The University also has designated offices to help you: [SafeCampus](#); [Office of the Ombud](#); [Title IX Investigation Office](#); and [University Complaint Investigation and Resolution Office](#).

Privacy Statement

This statement provided by the [UW Privacy Office](#).

This course may be recorded by the presenter. The recording will capture the presenter's audio, video, and computer screen. Student audio and video will be recorded if they share their computer audio and video during the recorded session. The recordings will only be accessible to students enrolled in the course to review materials. These recordings will not be shared with or accessible to the public.

The University provided Zoom and Panopto services have FERPA-compliant agreements in place to help protect security and privacy. Students who **do not** wish to be recorded in Zoom should:

- Choose a Zoom display name that does not include any personal identifying information like their name or UW Net ID; and
- Not share their computer audio or video during their Zoom sessions.