DSCI-534: Biomedical Data Privacy Issues and Solutions
Units: 4
FALL 2024

Instructor: Prof. Tatyana Ryutov
Time: 5:00-6:20pm
Days: Mondays
Office: ONLINE
Contact Info: tryutov@usc.edu
Course website: https://piazza.com/usc/fall2024/dsci534
Course Description
Privacy concerns in healthcare, current law and regulations, existing and emerging technologies shaped by ethics, privacy considerations, medical implications. Special attention given to genomic data.

Course Delivery
The class will be conducted online via Zoom. A general-purpose room is reserved for international students who must be present on campus to maintain their visa status. International students will be attending the class and delivering their presentations via Zoom while physically present in the assigned room.

Learning Objectives
After successfully completing this course, the students will be able to:
- comprehend the significance of privacy of medical data in healthcare;
- analyze privacy laws and governing regulations;
- identify the fundamental concepts and key issues of genomic privacy;
- apply the existing privacy preserving methodologies; and
- approach complex biomedical data privacy problems from these angles:
  - Data Vulnerability: Demonstrate how seemingly private information, can be discovered (or exploited) using automated strategies.
  - Data Protection: Select privacy protection technologies that provide formal computational guarantees of privacy in disclosed datasets.
  - Technology Policy Design: Apply privacy protection technologies that complement policy regulations.

Recommended Preparation
Prior experience with information security, public policy, and legal frameworks is not required for this course. Basic understanding of engineering and/or technology principles; basic programming skills at the level of DSCI 549 or DSCI 510 is preferred. Some background in informatics, data science, or computer science will be valuable.

All key concepts and relevant methodology will be reviewed and introduced throughout the course, however students should be comfortable learning about basics of human genetics, precision medicine, various cryptographic methods, and statistics.

Course Notes
This course will be conducted online, using a combination of synchronous and asynchronous methods. The remote learning format of this interdisciplinary course will eliminate the need for students attending different schools (e.g., Viterbi and Keck) to travel between campuses. Therefore, the course will continue to be offered online after the COVID restrictions are lifted.

Grading type: letter. Piazza (piazza.com) will be used for posting copies of lecture slides, announcements, assignments, and intra-class communication. Blackboard (blackboard.usc.edu) will be used for posting of grades, lecture recordings, homework submission, exam submission. Zoom (usc.zoom.us) will be used for lectures and office hours.

Technological Proficiency and Hardware/Software Required
Students must provide their own laptop. The laptop specifications take into consideration that students will be creating, streaming, and downloading audio and video, communicating using video-conferencing applications, and creating and storing large multimedia files.

Required Readings and Supplementary Materials
There is no primary textbook for this course. Reading assignments are selected from academic literature, various periodicals and other sources.
**Hours of Instruction**
Once weekly for 200 minutes including two 10-minute breaks.

**Class Participation**
Students are expected to actively participate in this course. Participation includes:
- Careful reading and viewing of assigned materials by the date due
- Regular, substantive contributions to discussions and in-class questions
- Active engagement with online content
Course grades for students who do not contribute to the course through active participation will be affected.

Pop out questions (about 6) will be asked during each lecture. Responses will be submitted using Google forms. The students will have 72 hours to submit their responses for each lecture. Failure to submit the responses on time will result in a deduction of the class participation score.

**Semester project**
Each student must complete a project on a data privacy issue in biomedicine. Projects should investigate a topic of interest to the student, and must demonstrate analysis and critical thought. Students may design their own project or choose from a predefined set of topics. A list of sample project topics will be made available and reviewed in class. This self-proposed semester-long project allows students to select either a research-oriented or implementation-oriented direction.

Work on the project will consist of several phases:
- **Project Proposal** *(due by week 5)*: The project proposal (2 pages) should include a description of the topic, what the student intends to do and how, contain preliminary references.
- **Written Project Status Report** *(due by week 9)*: A summary (6 pages) of the progress that was made.
- **Final Project Presentation**: Showcase of research methods and results.
  - **The lecture** will be devoted to individual student presentations. Students will be assigned specific date and time to present their findings by means of a power point presentation. Presentations will be assessed based on the peer review: each student will complete a brief survey providing their thoughts and reactions to the presentations.
- **Final Project Report** *(due on the last day of class)*: This will be in the form of a conference-style paper. It will summarize the research area, the methodology, experience, and contributions of your work.

**Final examination**
The final exam will be a two-hour written test administered via the USC Blackboard. The exam format will be a combination of short answers and essays.

Final exam date and time: refer to the final exam schedule in the USC Schedule of Classes at classes.usc.edu.

The exam can only be taken on the scheduled date and at the scheduled starting time. Accommodations for students with letters from DSP will be provided, though the exam will still need to be taken on the scheduled date and start time. There are no makeup exams. If you miss an exam due to a documented illness or an emergency, official written documentation will need to be submitted to instructor as soon as possible. Approval will be based on the instructor’s discretion.

**Grading Breakdown (preliminary)**

<table>
<thead>
<tr>
<th>Artifact</th>
<th>Weight</th>
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<tr>
<td>Final Exam</td>
<td>20%</td>
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</table>

Page 3
Homework Assignments & Class Participation & Semester Project & TOTAL 
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40% & 10% & 30% & 100%

**Grading Timeline**
None of the items in this class are auto graded. Assignments and the final exam will typically be graded within 7 days of the due date. Final project deliverables will typically be graded within 5 days of the due date. The class participation grades will typically be graded within 3 days after the end of classes.

**Assignment Submission Policy**
Assignments and semester project will be submitted electronically via Blackboard. Assignments will be accepted after the deadline with the following grade penalties. Cumulative of 10% times number of days late:
- 1 day late: lose 10%
- 2 days late: lose 30% (10% + 20%)
- 3 days late: lose 60% (30% + 30%)
- Greater than 4 days late not accepted

No personal emergencies will be entertained (with the exception of the USC granted emergencies, in which case official documents need to be shown).

**Diversity, Equity, and Inclusion (DEI) Statement**
Our classroom is a place to expand our knowledge and experiences safely, while being respected and valued. We proactively strive to construct a safe and inclusive learning environment by respecting each other’s dignity and privacy. We treat one another fairly and honor each member’s experiences, beliefs, perspectives, abilities, and backgrounds, regardless of race, religion, language, immigration status, sexual orientation, gender identification, ability status, socio-economic status, national identity, or any other identity markers.

Disruptive or insulting remarks, gender or racial slurs, or other forms of bullying, intimidation or hate speech and other disrespectful language or behavior will not be tolerated. We welcome your thoughts on how we can improve our learning environment.

**Additional Policies**
Class notes policy: Notes or recordings made by students based on a university class or lecture may only be made for purposes of individual or group study, or for other noncommercial purposes that reasonably arise from the student’s membership in the class or attendance at the university. This restriction also applies to any information distributed, disseminated, or in any way displayed for use in relationship to the class, whether obtained in class, via e-mail or otherwise on the Internet, or via any other medium. Actions in violation of this policy constitute a violation of the Student Conduct Code and may subject an individual or entity to university discipline and/or legal proceedings. Again, it is a violation of USC’s Academic Integrity Policies to share course materials with others without permission from the instructor.

**Participation**
Students are expected to actively participate in this course. Participation includes:
- Careful reading and viewing of assigned materials by the date due
- Regular, substantive contributions to discussions and in-class questions
- Active engagement with online content

Course grades for students who do not contribute to the course through active participation will be affected.

**Course Schedule: A Weekly Breakdown**
Class sequence, dates, reading assignments, and topics are subject to change as the semester proceeds. Any revisions will be noted and announced in class.

<table>
<thead>
<tr>
<th>Week</th>
<th>Topics</th>
<th>Readings</th>
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<tbody>
<tr>
<td>08/26</td>
<td><strong>Course introduction</strong></td>
<td>Required:</td>
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<tr>
<td></td>
<td>• Why do we need a course on</td>
<td>- [Benthall] S. Benthall, S. F. Gürses, H. Nissenbaum:</td>
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<td></td>
<td>• Data privacy definition</td>
<td>- [Schwartzshnaider] Schwartzshnaider, Y.; Apthorpe, N.; Feamster, N.; and</td>
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<td></td>
<td>• Privacy frameworks</td>
<td>Nissenbaum, H. I. “Going Against the (Appropriate) Flow: A Contextual</td>
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<td></td>
<td>• Models of data protection</td>
<td>Integrity Approach to Privacy Policy Analysis”, 2019.</td>
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<td>Optional:</td>
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<td>an enabler, not an impediment: building trust into health information</td>
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<td>exchange”, 2009.</td>
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<td>time for big decisions”, 2012.</td>
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<tr>
<td>9/2</td>
<td><strong>Legal aspects of privacy</strong></td>
<td>Required:</td>
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<td></td>
<td></td>
<td>- [UDHR] Universal Declaration of Human Rights,</td>
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<td>- [HIPAA] U.S. Department of Health and Human Services Summary of the</td>
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<td>Privacy Rule of the Health Information Portability and Accountability</td>
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<td>Act (HIPAA).</td>
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<tr>
<td>09/9</td>
<td>**Ethical principles and</td>
<td>Required:</td>
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<tr>
<td>Lec2</td>
<td>privacy**</td>
<td>- [Andrade] Gabriel Andrade, “Medical ethics and the trolley Problem”,</td>
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<td>2019.</td>
<td>HW1 due</td>
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<td>incidental findings in clinical exome and genome sequencing”, 2013.</td>
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<td>“To tell or not to tell? A systematic review of ethical reflections on</td>
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<td>incidental findings arising in genetics contexts”, 2013.</td>
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<td>Optional:</td>
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<td></td>
<td></td>
<td>- [PrivacyGenome] “Privacy and Progress in Whole Genome Sequencing”</td>
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<td></td>
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<td>participants: the floor, the ceiling, and the choices in between”, 2014.</td>
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<tr>
<td>09/16</td>
<td><strong>Genomic basics</strong></td>
<td>Required:</td>
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<td>Lec3</td>
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<td>- What is DNA? [Structure and Function of DNA],</td>
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<td><a href="https://www.youtube.com/watch?v=T6_wKPaBf2k">https://www.youtube.com/watch?v=T6_wKPaBf2k</a></td>
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<td></td>
<td></td>
<td>- Genes and the Genome,</td>
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<td><a href="https://www.youtube.com/watch?v=x1TQXBO6wQ">https://www.youtube.com/watch?v=x1TQXBO6wQ</a></td>
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<td></td>
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<td>- Alleles/Dominant/Heterozygous/Phenotypes and more!</td>
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<td><a href="https://www.youtube.com/watch?v=zNw0x5uQd8">https://www.youtube.com/watch?v=zNw0x5uQd8</a></td>
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<td>- What are DNA Mutations?,</td>
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<td><a href="https://www.youtube.com/watch?v=3wDl7nYBP">https://www.youtube.com/watch?v=3wDl7nYBP</a></td>
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<td>- Mutation and Haplotype,</td>
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<td><a href="https://www.youtube.com/watch?v=MeuQLeeYyq">https://www.youtube.com/watch?v=MeuQLeeYyq</a></td>
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<td>- Next Generation Sequencing (NGS) - Data Analysis,</td>
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<td>09/23</td>
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<td>Project Proposal due</td>
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<td>Lec4</td>
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<td>9/30 Lec5</td>
<td>Genomic privacy</td>
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<td>• Direct-to-Consumer Genomics and Legal Rights</td>
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<td>• Genomic (Big) Data Sharing</td>
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<td>• Informed consent</td>
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<tr>
<td>• Diversity, equity and inclusion in genomic research</td>
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**Required:**

**Optional:**

<table>
<thead>
<tr>
<th>10/7 Lec6</th>
<th>Basics of Information security</th>
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<tr>
<td>• Information security and privacy goals</td>
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<tr>
<td>• Authentication and identification</td>
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<td>• Access control models</td>
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<td>• Mandatory and discretionary controls</td>
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**Required:**

**Optional:**

**HW2 due**
<table>
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<tr>
<th>Date</th>
<th>Lecture</th>
<th>Topic</th>
<th>Required</th>
<th>Optional</th>
<th>Notes</th>
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</table>
| 10/14 | Lec7    | Information security tools | • Least privilege and separation of duties  
• Role based access control  
• Attribute based access control  
| 10/21 | Lec8    | Basics of Cryptography | • Encryption basics  
• Encryption tools for authentication, data confidentiality, integrity and non-repudiation  
• Attribute-based encryption | • Selected chapters from Kratikal Academy, “Cryptography: Data and Application Security”, 2017.  
| 10/28 | Lec9    | Cryptographic tools for privacy protection | • Homomorphic encryption  
• Cryptographic methods for secure multiparty computation  
| 11/4  | Lec10   | De-identification of biomedical data; Re-identification; Big Data record linkage; Inference and prediction of personal information | • De-identification: detect and suppress “identifiers” from unstructured data (e.g., clinical narratives  
• [Berman] Berman JJ. “Concept-match medical data scrubbing: how pathology text can be used in research”, 2003.  
<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
<th>References</th>
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<tr>
<td>11/11</td>
<td>No class, University Holiday</td>
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</table>
Optional:  
| 11/25     | Lec12 - Privacy Preserving Data Analysis   | • [Friedman] Friedman et al. "Providing k-Anonymity in Data Mining".  
Optional:  
| 12/2      | Lec 13 - Project Presentations             | Required:  
• TBD  |
| Final     | Final Examination                         | December 16, 4:30-6:30pm  |

**Academic Conduct**

Plagiarism – presenting someone else’s ideas as your own, either verbatim or recast in your own words – is a serious academic offense with serious consequences. Please familiarize yourself with the discussion of plagiarism in SCampus in Part B, Section 11, “Behavior Violating University Standards” policy.usc.edu/scampus-part-b. Other forms of academic dishonesty are equally unacceptable. See
additional information in SCampus and university policies on scientific misconduct, [policy.usc.edu/scientific-misconduct](http://policy.usc.edu/scientific-misconduct).

Plagiarism includes the submission of code or written assignments obtained from someone else, including sources like ChatGPT. **Use of generative AI is not permitted in this course.**

**Students with Disabilities**
Any student requesting academic accommodations based on a disability is required to register with Disability Services and Programs (DSP) each semester. A letter of verification for approved accommodations can be obtained from DSP. Please be sure the letter is delivered to me as early in the semester as possible. Your letter must be specific as to the nature of any accommodations granted. DSP is located in STU 301 and is open 8:30 am to 5:30 pm, Monday through Friday. The telephone number for DSP is (213) 740-0776.

**Learning Experience Evaluations**
Learning Experience Evaluations will be completed during the last day of class. This will be your opportunity to provide feedback about your learning experience in the class. This feedback helps the instructor determine whether students are having the intended learning experiences for the class. It is important to remember that the learning process is collaborative and requires significant effort from the instructor, individual students, and the class as a whole. Students should provide a thoughtful assessment of their experience, as well as of their own effort, with comments focused on specific aspects of instruction or the course. Comments on personal characteristics of the instructor are not appropriate and will not be considered. For this feedback to be as comprehensive as possible, all students should complete the evaluation.

**Support Systems**
* Counseling and Mental Health - (213) 740-9355 – 24/7 on call [studenthealth.usc.edu/counseling](http://studenthealth.usc.edu/counseling)  
Free and confidential mental health treatment for students, including short-term psychotherapy, group counseling, stress fitness workshops, and crisis intervention.

* National Suicide Prevention Lifeline - 1 (800) 273-8255 – 24/7 on call [suicidepreventionlifeline.org](http://suicidepreventionlifeline.org)  
Free and confidential emotional support to people in suicidal crisis or emotional distress 24 hours a day, 7 days a week.

* Relationship and Sexual Violence Prevention and Services (RSVP) - (213) 740-9355(WELL), press “0” after hours – 24/7 on call [studenthealth.usc.edu/sexual-assault](http://studenthealth.usc.edu/sexual-assault)  
Free and confidential therapy services, workshops, and training for situations related to gender-based harm.

* Office of Equity and Diversity (OED)- (213) 740-5086 | Title IX – (213) 821-8298  
[equity.usc.edu](http://equity.usc.edu), titleix.usc.edu  
Information about how to get help or help someone affected by harassment or discrimination, rights of protected classes, reporting options, and additional resources for students, faculty, staff, visitors, and applicants. The university prohibits discrimination or harassment based on the following protected characteristics: race, color, national origin, ancestry, religion, sex, gender, gender identity, gender expression, sexual orientation, age, physical disability, medical condition, mental disability, marital status, pregnancy, veteran status, genetic information, and any other characteristic which may be specified in applicable laws and governmental regulations. The university also prohibits sexual assault, non-consensual sexual contact, sexual misconduct, intimate partner violence, stalking, malicious dissuasion, retaliation, and violation of interim measures.
Reporting Incidents of Bias or Harassment - (213) 740-5086 or (213) 821-8298
usc-advocate.simplicity.com/care_report
Avenue to report incidents of bias, hate crimes, and microaggressions to the Office of Equity and Diversity |Title IX for appropriate investigation, supportive measures, and response.

The Office of Disability Services and Programs - (213) 740-0776
dsp.usc.edu
Support and accommodations for students with disabilities. Services include assistance in providing readers/notetakers/interpreters, special accommodations for test taking needs, assistance with architectural barriers, assistive technology, and support for individual needs.

USC Support and Advocacy - (213) 821-4710
uscsa.usc.edu
Assists students and families in resolving complex personal, financial, and academic issues adversely affecting their success as a student.

Diversity at USC - (213) 740-2101
diversity.usc.edu
Information on events, programs and training, the Provost’s Diversity and Inclusion Council, Diversity Liaisons for each academic school, chronology, participation, and various resources for students.

USC Emergency - UPC: (213) 740-4321, HSC: (323) 442-1000 – 24/7 on call
dps.usc.edu, emergency.usc.edu
Emergency assistance and avenue to report a crime. Latest updates regarding safety, including ways in which instruction will be continued if an officially declared emergency makes travel to campus infeasible.

USC Department of Public Safety - UPC: (213) 740-6000, HSC: (323) 442-120 – 24/7 on call
dps.usc.edu
Non-emergency assistance or information.