

<b>Course description</b>	<p>Should all our genetic information be made public in order to eradicate genetic diseases from this world? Who owns your genetic data once it becomes publicly accessible? What is your responsibility to family members when you know more about genetic diseases than they do? Who decides what kind of genetic information is relevant to a person? And what does genetic privacy mean to you?</p> <p>In this course we will critically reflect upon the issue of genetic privacy. We will dive into the ethical questions that come up with the disclosure of genetic data in biobanks and through genetic tests.</p>			
<b>Domain</b>	Humanities, Ethics, Arts and Culture, Biotechnology			
<b>Keywords</b>	Privacy	Genetics	Ethics	Art
<b>Prerequisites</b>	<p>This course can be taken by:</p> <ul style="list-style-type: none"> <li>• The course is for people who are interested in broadening and deepening their understanding of implications of biotechnological developments on society, specifically with regard to genetic research and privacy issues.</li> <li>• The course does not require previous knowledge of the subject. It is for those willing to explore scientific, ethical and artistic issues in a critical manner and to have a debate with people around the world.</li> </ul>			
<b>Level</b>	Bachelor			
<b>Language</b>	English			
<b>Number of credits and workload</b>	5 credits	10-15 hrs per week	140 hrs in total	
<b>Semester period and Start date course</b>	Semester 2	<b>Start date:</b> 15 February 2019 up to and including 15 March 2019		
<b>Application deadline</b>	4 February 2019			
<b>Full course description</b>	<p>Should all our genetic information be made public in order to eradicate genetic diseases from this world? Who owns your genetic data once it becomes publicly accessible? What is your responsibility to family members when you know more about genetic diseases than they do? Who decides what kind of genetic information is relevant to a person? And what does genetic privacy mean to you?</p> <p>In this course we will critically reflect upon the issue of genetic privacy. We will dive into the ethical questions that come up with the disclosure of genetic data in biobanks and through genetic tests. This course encourages the participants to think about the cultural, philosophical and political tensions present in the debate around genetic privacy. The participants are invited to identify and listen to the viewpoints and values provided by the different stakeholders that shape this debate: corporations, researchers, consumers and patients. Furthermore, the participants will go off the beaten track by exploring the issue from the unique perspective of art and culture. The end assignment is to write a recommendation on how to regulate practices of disclosing genetic information, while taking into consideration the concept of genetic privacy.</p> <p><b>Course objectives</b> The student:</p> <ul style="list-style-type: none"> <li>• will be able to signal ethical issues and controversies around genetic privacy;</li> <li>• will be able to reflect on biotechnological practices and the issue of genetic privacy by discussing art that engages with biotechnology;</li> <li>• will be able to reflect on genetic privacy from perspectives of ethical and moral frameworks;</li> <li>• will gain insights into social and cultural implications of genetic privacy by analyzing art works;</li> </ul>			

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	<ul style="list-style-type: none"> <li>will broaden her/his perspective on the relationship between art, the humanities, biotechnology and society by working in interdisciplinary groups of students.</li> </ul>		
<b>Platform and link to course description</b>	Blackboard	<a href="https://blackboard.leidenuniv.nl/webapps/portal/execute/tabs/tabAction?tab_group_id=81">https://blackboard.leidenuniv.nl/webapps/portal/execute/tabs/tabAction?tab_group_id= 8 1</a>	
<b>Course description in study guide</b>	<a href="https://studiegids.leidenuniv.nl/courses/show/88865/genetic-privacy-should-we-be-concerned">https://studiegids.leidenuniv.nl/courses/show/88865/genetic-privacy-should-we-be-concerned</a>		
<b>Lecturer(s)</b>	Prof. dr. Ing. Robert Zwijnenberg Dr. A.A. Wolodzko		
<b>Extra Course information</b>	<p><b>Mode of instruction</b></p> <p>Seminars and (on-line) lectures. Students will participate in the MOOC Genetic Privacy (an online learning experience freely available on the Coursera Platform. Students are asked to prepare each weekly class session by viewing the videos sessions of the MOOC before class and preparing the MOOC assignments in advance. In class we will discuss the prepared assignments and the assigned literature. Each student must write a policy advice how to regulate genetic privacy, taking into consideration the materials of the MOOC and the assigned literature.</p>		
<b>Picture of course</b>			
<b>Final examination date and time /period</b>	Deadline for handing in final assignment: <b>29 March 2019</b>	Examination time UTC + or -	Examination period in case date is not yet known
<b>Examination registration deadline or drop-out deadline</b>	Examination registration before - Drop- out deadline -		
<b>Type of examination</b>	Participation and Presentations in class: 20%; <ul style="list-style-type: none"> <li>Final presentation: 30%;</li> <li>Individual : policy advice 50%.</li> <li>If the final grade is insufficient (lower than a 6), there is the possibility of retaking the final essay.</li> </ul> Contact the course lecturer for more information.		
<b>Midterm examination ?</b>	<input type="checkbox"/> yes <input type="checkbox"/> no		
<b>Previous exam papers available</b>	<input type="checkbox"/> yes <input type="checkbox"/> no		
<b>Specific rules for</b>			

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examinations		
Resit? and date	<input checked="" type="checkbox"/> yes <input type="checkbox"/> no	
Grade release and transcript release		

Available Places	Total number of places : 12	
	Interested	12 places in total
Adelaide	<input type="checkbox"/> yes	
ANU	<input type="checkbox"/> yes	
EPFL	<input type="checkbox"/> yes	
HKUST	<input type="checkbox"/> yes	
Leiden	<input type="checkbox"/> yes	
Rice	<input type="checkbox"/> yes	
TU Delft	<input type="checkbox"/> yes	
UQ	<input type="checkbox"/> yes	
Wageningen	<input type="checkbox"/> yes	