

Health, Humanism, and Society Scholars - Project Submission Form

Project Title: Ethics and Decision Making

Project Description:

Dr. Blumenthal-Barby is working on several projects related to medical decision making and ethics. The student(s) selected to work on this research team may participate in helping with any one or several of these projects depending on need and timing.

Students: Please note on your essay which project(s) you're interested in. If you're interested in all 3 that is OK, or if you're unsure but would like to talk with the host more during the interview process that is OK too. Because all three of these projects are with one host team, an application for this posting will only count as one of your 6 total project selections.

One project involves studying the use of a "decision aid" (DA) to help improve decision making about placement of a ventricular assist device ("LVAD") among end stage heart failure patients. We developed a DA (www.lvaddecisionaid.com) and conducted a randomized trial of the DA vs. standard education and found that the DA improved patient knowledge and that both patients and clinicians viewed the DA favorably and we then worked with 10 sites to integrate it into their regular clinical flow. For the current project, we are studying the integration of a web-based "personalized risk calculator" that uses artificial intelligence/machine learning to predict individual patient outcomes, as well as the integration of a "personalized values clarification exercise." The student could assist with various aspects of this project, which may include literature reviews and summaries, assistance in data presentation (e.g., tables, figures), assistance with tracking activities, assistance with coding and analyzing interviews, collaborative paper writing, and development of web-based resources and activities. The student would attend weekly research team meetings.

A second project involves studying ethics and decision-making related to *pediatric deep brain stimulation for dystonia and OCD*. We interviewed stakeholders (parents, clinicians) and are in the process of developing a decision aid to guide this difficult decision. The student could assist in various related research tasks such as literature reviews and summaries, coding interviews, collaborative paper writing, and assisting in decision aid development. There is also the opportunity for exploration of a related topic: the ethics of first-in human neuro-device trials. The student would also attend weekly research team meetings.

Finally, Dr. Blumemthal-Barby is developing a "*Philosophical Bioethics Network/Hub*," which will be an active web platform for resources and content in philosophical bioethics. This is a



collaborative effort with other leading Centers in philosophical bioethics. There may be opportunity for student involvement here.

Institution and Location: Baylor College of Medicine, Center for Medical Ethics and Health Policy

<u>Prerequisite training</u>: Interests and/or coursework related to the above topics will be prioritized. Students should be enthusiastic, organized, detail-oriented, self-motivated, adaptable, punctual, professional, willing to be flexible and adaptable (some research tasks are more fun than others, and these projects involves a mix of research streams), and have excellent writing skills.

Knowledge and skills student can expect to gain: Insight into how research teams function, how research ideas are generated and executed, the day to day work of research and translation of research results into practice, searching and summarizing literature, knowledge about medical decision making/psychology/ethics, potentially experience analyzing and coding qualitative data, networking opportunities.

Expectations of student (Rice University requirements are listed):

• The student must devote 8 hours per week to the project (consistent with a 3-credit course) and will develop a timeline of activities in collaboration with supervisor(s). The student will meet at least monthly with the faculty supervisor(s) to evaluate progress.

Expectations of PIs/project sponsors:

• The projects should be designed with the academic rigor of Rice University in mind, and abide by the U.S. Department of Labor's Fair Labor Standards Act for unpaid internships. Mid-semester and final supervisor evaluations will be submitted to evaluate student's professional progress. Complete details found here: Project Sponsor Eligibility.