## Consortium on Law and Values in Health, Environment & the Life Sciences Award Report for the 2017-18 Academic Year

"Negotiating Responsibility: Ethics of Choice and Care in Postsocialist Oncology Wards in Serbia" Milica Milic Anthropology/ CLA PhD program

## **Project Summary**

My project focuses on observing the interactions between patients and their doctors within oncology clinics to analyse how the practice of informed consent gets understood and realized in a context of pharmaceutical trials in contemporary Serbia. Specifically, as Serbia is a postsocialist country, with a particular history of governing practices and a constant political negotiation with both the Eastern Bloc and "the West", I observed ideas about collective and personal responsibility as well as professional and institutional authority. By looking at how are global pharmaceutical practices pertained to pharmaceutical research, most notably the practice of informed consent, I have examined the changing (and at times enduring) socialist rhetoric of ethics of care. During summer of 2018, I have completed extensive fieldwork that consisted of in depth interviews and participant observation in two largest oncology clinics in Serbia, VMA and Kamenica Institute, as well as repeated interviews with the informants I have interacted between 2014 - 2017.

## **Results**

During my fieldwork in summer 2018, I have completed 72 interviews with oncology patients and their doctors. I am currently working on analyzing this data in order to write chapter three of my dissertation. My findings have already informed chapters one and two of my dissertation. Since completing the fieldwork funded by the Consortium I have presented my research at the American Anthropological Association Annual meeting in November 2018 and SOYUZ conference in March 2019. While many of the data I collected does align with my previous findings, during summer 2018 I have examined various ways in which the understandings of institutional authority shape the way in which informed consent will be actualised and narrativized. I found that oncology patients not only expect the doctors to make decisions for them, but rather feel like they are "entitled" to be taken care of, which entails not having to be "burdened" by decision making. This is further shedding light onto posticislist ideology of professional responsibility and points to the necessity of completing extensive research with the following intellectual question as focus: How can global pharmaceutical practices of medical research and clinical trials be modified to make sense in a specific context of postsocialist division of labor and alleged "deferral of responsibility?"

## Future project plans

The research completed has informed chapters one, two and three of my dissertation which will consist of five substantial chapters, an introduction and conclusion. I have completed an outline of my dissertation and drafts of chapters one and two. Goal date for completing my dissertation is August 2020. I plan to revise four out of five chapters and submit them to American Ethnologist and Medical Anthropology for publication during Fall 2019 and Spring 2020. The research I conducted has opened new analytical questions

relevant for my academic interests. Most importantly I have gained insight into how ideas about personal and collective responsibility are produced in an informal setting, through discursive practices of memory and nostalgia. However, I have not specifically addressed how these ideas get perpetuated and reinforced in a formal setting - through educational systems. Hence, my future research will focus on the analysis of higher education and the pedagogy behind ethics classes designed for students of medicine. Simultaneously, I will analyze the approaches that professors take in discussing topics of medical research, individual choice and voluntary participation as well as the ways in which these discussions are understood by the student body. This will help me shed more light on the complex dynamic between authority and individual responsibility, as practiced and understood in the context of postsocialist, "neoliberal to be", Serbia, with a focus on pharmaceutical trials. Ideally, my postdoctoral research will be dedicated to exploring ideas and questions that have emerged from the fieldwork I conducted in summer 2018.