

# Consortium on Law and Values in Health, Environment & the Life Sciences 2017-18 Student Proposal Cover Page

## Applicant Information

Applicant name(s):	Milica Milic	Email:	mili0020@umn.edu
Project title:	Negotiating Responsibility: Ethics of Choice and Care in Postsocialist Oncology Wards in Serbia		
Department:	Anthropology	College:	CLA
Degree program:	PhD program		
Faculty advisor:	Karen-Sue Taussig	Faculty advisor email	taussig@umn.edu <input type="checkbox"/> No advisor
Dept. Head:	Karen-Sue Taussig	Dept. Head's email:	taussig@umn.edu
Dean:	John J. Coleman	Dean's email:	coleman@umn.edu

How did you hear about this funding opportunity?  
 Consortium e-mail  Consortium website  The Brief  Dept. email/newsletter  Other (specify)

Total amount of funding requested: **\$5000**

Executive summary (maximum 200 words)

Legal foundations of medical research and scientific development have been changed significantly to the favor of acknowledging of the vulnerability of particular populations. Medical research on human subjects is becoming more cognizant of issues of coercion, conflicts of interest and translatability of medical language for the purpose of achieving the goal of informed consent and voluntary participation. Still, informed consent and practices of global pharmaceutical trials are understood, adapted and exercised under different cultural, historical and ideological assumptions about the body, illness and medicine. I examine the influence that transnational and global connections have on the postsocialist Serbian medical system. I show that simultaneously existing, and intertwined, narratives about “good” socialist citizen and an active, self-responsible neoliberal subject complicate the current understandings of transition, observed in the relationship between citizens and the state in particular context of changing medical system and an ethics of care. I argue that in this context of long standing Serbian tradition of biomedical approach to treatment, illness and the body, but with particular ideas about authority, state and personal and collective responsibility, practice of informed consent has to be re-examined and observed with specific attention to expectations that doctors and patients place on each other.

## Approvals

*Check all appropriate approvals required for your proposal. It is not necessary to have all approvals at the time of proposal submission; however, approvals must be obtained prior to receipt of funding. If you have applied for approval but have not yet received it, indicate that below.*

IRB	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA	<input type="checkbox"/> Application pending	
Other	<input checked="" type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> NA	<input type="checkbox"/> Application pending	Specify: IRB approval from two oncology clinics in Serbia: VMA and Kamenica Institut (where I conducted long term fieldwork and will conduct the follow up study)

## Checklist—for reviewer use

- The proposal is 1000 words or less excluding budget, biographies, references and citations.
- The proposal includes a work plan with a specific timeline using months or quarters to identify work to be done and completion dates.
- The proposal includes a 1-2 paragraph biography of the applicant and all co-investigators.
- The budget form is complete including the funds sought for this project, other pending applications for this project, and the amount/source of matching or other funds.
- The applicant's faculty advisor is copied on the application email. Professional students w/o advisors check No Advisor.
- All necessary approvals are pending or received.

**Background and Importance:** Medical research and pursuit for knowledge has had a very complicated and controversial history (e.g. Shuster, 1997; Weindling, 2001). Still, modern day clinical pharmaceutical trials remain a scientific practice that embodies controversy regarding the goals and ethics of developing medication and treatment. Specifically, I argue that the discussions regarding ethics of pharmaceutical research mainly focus on the following issues: 1) Targeting of vulnerable groups (e.g. Rice 2008); 2) Marketing trials to developing countries and thus causing problems of literal and cultural translatability. (e.g. Kleinig 2010) 3) Exploitation - use of bodies for scientific development after which those same bodies will be denied access to developed treatment they participated in producing. (e.g. Biehl and Petryna 2011)

However, what these studies do not address directly are the postsocialist countries in transition and its ideological context that strongly affects the way in which pharmaceutical trials will be interpreted, understood and practiced. Concretely, many of these countries have a long history of biomedical approach to body and illness that follows (and simultaneously develops next to) Euro-American medical practices and research. By only looking at these countries as economically and scientifically underdeveloped, and ignoring the ideological context, what is at stake when thinking about pharmaceutical research in these countries has been under-analyzed and obscured by the literature on ethics, life sciences, health and history of medicine.

Pharmaceutical trials have, for decades now, targeted countries in transition in Eastern Europe. A rich body of scholarship addresses this shift in the global practices of pharmaceutical trials (e.g. Petryna, Lakoff, Kleinman 2006). The reasoning behind it is an alleged saturation of consumption of medications in West Europe and US context. On the contrary, countries in Eastern Europe offer “naive bodies” - human subjects that are allegedly underexposed to pharmacological contents, and thus are more reliable sources of information when participating in clinical trials.

States in transition, such as Serbia, a post-Yugoslav country, offer a fruitful site for examining the everyday commitments and experiences that shape the ideas about citizenship, responsibility and authority in the field of medicine. The oncology clinic offers a particularly valuable avenue into these issues. Not only is it a domain in which public and private healthcare now exist simultaneously along with global pharmaceutical trials, but what is at stake is life and death. In the changing setting of ethics of care, physicians and patients regularly articulate the expectations they have of each other to navigate the transition, and make sense of the changing medical practices and an ethics of care.

**Methodology and data:** To examine the context of Serbian oncology clinics, privatization of healthcare and Euro-American pharmaceutical research in the region my fieldwork has focused on the dichotomous medical system in Serbia, while the universal health care maintains its dominant role in the public opinion. I have spent a year conducting extensive fieldwork since September 2016 - August 2017 and have had in depth interviews with more than two hundred oncology patients, their doctors, nurses and young practitioners in training. The data I collected shows that the ways responsibility and decision-making processes are interpreted by oncology patients and their doctors speak to a complex and dynamic relationship involving socialist ideas of authority and neoliberal ideas of individual agency. Specifically, many of my informants have shown surprise that I am interested in how they get informed about their treatment sharing their opinion that it is not “their job - it is the doctor’s job to decide/know/direct”, and telling me that participation in clinical trials is something they are not sure about: “Ah, now that you mention it I might be in [a clinical trial]. ... You know, when I got here, I felt as if I am already cured and I put myself in their hands completely.”

I have been using standard ethnographic methodological approaches of in-depth interview and observation and participation. I will use textual and discursive analysis of

the data I have and will collect in the future: fieldnotes, audio recordings, ethnographic notes.

**Proposed work:** My project demands a three month ethnographic follow up study during summer 2018 and a two month period of data analysis and writing up. My informants have been in different stages of their treatment and with various experiences in dealing with the medical sphere when I conducted my initial fieldwork, so it is of great importance to observe if and how do their narratives change over time. Further, I will analyse the collected data with respect to relevant literature in anthropology, ethics, history, transition, life sciences and health.

June, July, August 2018 - data collection: follow up interviews

December 2018 and January 2019 - data analysis and write up

**Contribution and innovativeness:** My project investigates the often taken for granted, assumptions about individual agency in the realms of the body, disease and medicine (Balshem 1993; Livingston 2012; Mattingly 2010; Rose 2007). I observe the relationship between ideas about the ethical and the legal as they are worked out in the context of informed consent and clinical trials, a context shaped by particular ideas of ethics and individual responsibility (Ong and Collier, 2005; Petryna 2009), and examine what patients imagine to be their own role and what they consider the responsibility of the national medical system and the Serbian nation.

Finally, this projects shows that the way the rhetoric of “naive bodies” has been used to facilitate the outsourcing of clinical trials to Eastern Europe has to be brought into question. With my particular analysis of oncology clinical trials, in which patients sometimes deal with cancer and chemotherapy for years, underexposure to pharmacological content as a rationale becomes not only logistically and scientifically, but much more ethically and legally a problematic one. Thus, my projects aims to scrutinize the practice of informed consent and argues that the complicity, obedience and specific ideas about professional and personal responsibility, as discussed by significant body of scholarship (Trnka and Trundle 2014; Foucault 2008; Mitchell 1999; Miller 2008) greatly influences the global movement of pharmaceutical trials.

**Biography:** Milica Milic, the PI of the project, is in her 5th year in the PhD program in Anthropology department. She is moving through the program in a timely manner and has obtained her PhD candidacy in September 2016. She has completed pilot fieldwork and long term fieldwork which has equipped her with the skills and knowledge necessary to bring this project to its completion. Throughout the years her work has been funded by internal University fellowships (CLA, Berdahl and Hella Mears) and external grants (Open Society Foundation). She has participated in a number of conferences in which she presented her work and has served as a peer reviewer for Anthropology Matters in 2016, which demonstrates that she is a graduate student that is working on becoming an accomplished scholar.

#### **Key references:**

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