

## Crowdsourcing for Health Scientists and Patients Reconfiguring Trials and Regulatory Practices

FU-Berlin, Monday, 11<sup>th</sup> of July 2016, 14:00-17:00  
Habelschwerdter Allee 45, 14195 Berlin  
Room K 23/27

Speakers: Dr. Annamaria Carusi - University of Sheffield, UK  
Dr. Giovanni De Grandis - Norwegian University of Science and Technology

Organizer: Dr. Flavio D'Abramo

Please register your attendance writing at: [flavio.dabramo@fu-berlin.de](mailto:flavio.dabramo@fu-berlin.de)

Recently the relation between science and society has been the focus of considerable reflection and important changes. There are many reasons and motives for these attention and transformations. Among them the aspiration to give more voice to democratic citizens in the shaping and orienting scientific and technological innovation has played an important role. The emergence and enormous success of internet-based digital technologies has been another main driver.

Crowdsourcing is perhaps one of the most successful examples of an internet enabled practice that has considerable promise both in involving and empowering citizens, and in feeding into research information about the real world and dispersed, local knowledge. At a time when science and technology are under pressure to have a social impact and to contribute to tackling grand challenges and social problems, this opens up interesting possibilities. Most notably crowdsourcing can contribute to the production of knowledge and innovation that can work not only in controlled circumstances (as epitomised by the lab) but also in uncontrolled, "wild" and culturally laden, environments, thus easing the translation of knowledge into practices and the uptake of technological innovation. The prospects of less abstract science and more context-sensitive technology are clearly attractive. However, they present some serious challenges as well. One has to do with the quality of data and information that is included: to catch more information about reality we often have to include less controlled information. We thus face a trade-off between aiming for better external validity and keeping up the epistemological standard of good, reliable science (but reliable in what circumstances?). Another important issue has to do with how inclusive these digital technologies are and hence of how to deal with asymmetries and barriers in access and selection bias that they can easily bring into technoscientific work. This is an issue where the link between epistemological, ethical and political issues become especially visible. More generally the problem is that science and technology for the real world, for *improving* the real world, are science and technology that have to be adapted to a world wrought with contingencies and injustices, with the risk that these latter are incorporated in the production of scientific knowledge and technological artifacts. This may well generate vicious cycles.

The workshop has two aims:

1. It presents a recently funded seed project that broaches the epistemic and ethical issues of crowdsourcing in biomedical research, more specifically in clinical trials and regulatory practices. Since a main goal of the project is to build an international network and generate further research projects, this is an interesting opportunity for anybody interested in the epistemology and ethics of crowdsourcing.
2. It attempts to stimulate discussion both about the experiences and challenges of those who are using or affected by these new crowdsourcing technologies and practices, and about the broader social, political, economic and cultural circumstances in which these new technologies and new scientific methodologies are developed and used.

## Crowdsourcing for Health Scientists and Patients Reconfiguring Trials and Regulatory Practices

FU-Berlin, Monday, 11<sup>th</sup> of July 2016, 14:00-17:00  
Habelschwerdter Allee 45, 14195 Berlin  
Room K 23/27

**Programm:** 14:00-14:15 Introduction  
14:15-14:45 Presentation of the speakers  
14:45-15:15 Presentation of the project "Crowdsourcing for health"  
15:15-15:30 Break  
15:30-17:00 Q&A

**Annamaria Carusi** (MA, PhD) has a broad humanities background, ranging from philosophy to critical and literary theory. She is reader in Medical Humanities at the University of Sheffield. Her recent research has focused on images, models, simulations and visualisations in the contemporary biosciences, and on the role of technologies in computationally intensive interdisciplinary settings. Her work is highly interdisciplinary, and she has close collaborations in the broad field of science studies, as well as with scientists. Annamaria is leading the Crowdsourcing for Health project.

**Giovanni De Grandis** (MA, PhD) is postdoctoral researcher at the Norwegian University of Science and Technology (NTNU). Trained in Philosophy, he has done research on the uptake of digital technologies in philosophical scholarship, in transdisciplinary integration and in the ethical and political aspects of health policy. He is currently working on a project addressing the ethical and political aspects of personalised medicine. Giovanni is the main researcher in the Crowdsourcing for Health project.

### *Abstract of the project*

Crowdsourcing is reshaping key gatekeeping mechanisms in healthcare such as regulatory tests and clinical trials. This project will compare the science and patient communities in order to identify the main opportunities and challenges for healthcare of this redistribution of knowledge for healthcare. The project focuses on the inter-relationship between epistemic, social, pragmatic and ethical drivers in four main areas:

1. distribution and assessment of information and knowledge,
2. integrity and robustness of research,
3. ethical questions raised by the allocation of responsibility and the management of risk,
4. social acceptance and adoption of new modes of knowledge gatekeeping by scientists and patients.

The main activities of the project are i) to conduct comparative pilot studies of an emerging science community crowdsourcing information and knowledge for regulatory tests for drug assessment, and of patient communities that have produced patient-led clinical trials and similar initiatives that inform patient choices and apply pressure on healthcare providers, and ii) to build an interdisciplinary and international community of researchers who will be in a position to collaborate on key questions and challenges in crowdsourcing for health, and inform the ongoing development of these resources.