# III Workshop of the M<sub>3</sub>O Research Group: **Responsible Research and Innovation (RRI)**



Grup de Recerca M₃O Methodology, Methods, Models and Outcomes of Health and Social Sciences UVIC:UCC

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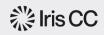
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# **Rosina Malagrida**

Head of Living Lab for Health at the IrsiCaixa Research Institute and co-coordinator of Barcelona CaixaResearch Living Lab

### **Ester Busquets**

Coordinator of the M₃O Research Group and coordinator of the Chair in Bioethics Fundació Grifols at UVic-UCC Heading towards "Responsible Research and Innovation" is a conceptual framework interrelated with other movements that are happening all over the world, having in common the fact that they are all willing to increase the impact of research and innovation. Rosina introduced the topic by explaining problems that have become persistent and that make goals impossible to achieve due to challenges that have not previously been successfully faced. She insisted on being open and transparent to designing and developing a research project making the stakeholders more participative and active in the research. In order to create a participative environment among the stakeholders, it is important to use collaborative spaces which are not always easy to establish. Such collaborative spaces will help to achieve the goals of the project and will consider the needs and opinions of the stakeholders.

Ester spoke about the importance of ethics in research, explaining how essential it is for the progress of humanity and its relationship with ethics, taking into account the means and ends that created the need for ethics in research. She explained that during the trial on Nazi human experimentation, the first Nuremberg code document was born, setting criteria to establish that the end does not justify the means. After Nuremberg there have been many other experiments where ethics have not been respected. Currently, in some countries experiments continue to be carried out without taking them into account. Ethics is based on not doing harm to the person, on creating a methodologically well-designed study that has a selection of participants, that studies the risk-benefit relationship, uses informed consent, respects privacy, and in which an ethics committee evaluates and monitors the study.

# **Mireia Canals**

Member of Gender Studies Group: Translation, Literature, History and Communication (GETLIHC)

# Magdalena Walbaum

Research Officer in Social Care at the London School of Economics and Political Science (LSE) Mireia talked about how to integrate gender in research, a case study called ResiCOVID. Talking about gender in research is necessary nowadays because promoting gender equality in teams and at all levels of research careers guarantees gender balance in decision-making positions and it integrates gender into the scientific research content. She explained the meaning of gender-sensitive research, which should eliminate androcentric biases in its design, content and results, considering the dimensions within gender and multiple social backgrounds in all the phases of the project.

Some of the positive outcomes will be favoring innovative research since it takes into account unusual points of view, makes visible the power relations present in the research processes, analyzes realities, and provides the elements to empower its participants.

Magdalena's presentation was about a practical example of an already completed project called "Changing the funded healthcare provision in Chile for people with chronic kidney disease". Chile has a problem with financial support: when kidney disease progresses to stage 5 there is no treatment, and they just carry out secondary treatment without receiving a specific treatment for it. Thus, the main problems are people starting treatment in the early stages, when they do not require it, and other people are stuck on the same type of treatment even if they require a different one. This creates the need for renal replacement treatment when it could have been avoided or could have reduced progression before that. These types of treatments have an impact since dialysis means attending three times a week or more for three or four hours. In order to solve these problems, they could change the law including the conservative or pre-dialysis treatment for stages 4 and 5 and then introduce some drugs for stage 3, 3A and 3B to reduce the progression. This model had the aim of introducing a new method of evaluation for decision-making in the AUGE regime.

# **Adelina Comas**

Assistant Professorial Research Fellow at Care Policy and Evaluation Centre (CPEC), Department of Health Policy London School of Economics and Political Science (LSE)

# Maria Giné

Physiotherapist and Principal Investigator of the Health, Physical Activity and Sport Research Group (SAFE) at Blanquerna-Ramon Llull University

Adelina presented her topic (Governance) using the theory of change to co-produce research, a monitoring and evaluation approach in response to "the black box" evaluation of programs, understanding how and why a program brings about change, also capturing the knowledge of stakeholders that can help you bring together this knowledge and develop this theory. She insisted on gathering a wide range of experiences and expertise because it is important to co-develop a theory of change. This theory is not an organized method to try to understand all these bits and capture all the knowledge about it. She defined the theory of change as an outcomes-based approach that describes how a program brings about specific outcomes through a logical sequence of intermediate outcomes. She usually presents this theory through workshops with stakeholders. The better defined, the better your theory of change will be. Nowadays it has been used in more ways than it was originally devised.

Maria's presentation aimed to give an overview of what citizen science is and about co-creation as a form of citizen science. She defined co-creation as a radical shift in scientific paradigms from an evidence-based top-down approach toward more open science. She explained citizen participation in science as an occurrence at different stages of the research project and at different levels of involvement, which may involve citizens and relevant stakeholders with different forms of participation. She made special mention of how important it is to incorporate the voices of people affected by public health problems because people's lived external knowledge adds value to the research, and it also has an ethical imperative. Doing so can generate an impact in research that will directly affect their well-being. Despite this, this approach is currently still not the norm in the scientific field. In general, the research question, the design and the implementation of research projects do not actively consider patients' carers or relevant stakeholders as members of the team that defines the aim or methods designed. The definition of citizen science involves collaboration, but it also needs to be under the direction of professional scientists. This is different from co-creation, which involves knowledge production among diverse stakeholders, the content is shared and transdisciplinary, and the production of knowledge is more equitable.

# Diana Szakál

Researcher at the Environmental Social Science Research Group (ESSRG Budapest, Hungary)

Diana talked about science education in the context of responsible research and innovation, why it is important and crucial, and how we can all engage with it. There are a lot of different ways to engage with science and education, and the main aim is to bring different types of knowledge together and create something that is even better than what we could create by using just one field. The mainstream is not only sharing specific scientific field-related knowledge but also supporting citizens and participants in developing skills and competencies to empower participation. Diana considers science education important because we have so many challenges and threats that we are facing together as a planet and as humanity that we need to create innovative solutions. Many of the problems in the world had been co-created by people, so it is important to come together to co-create new solutions in which science education and all types of learning environments play a really important role.

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