

People-Centered Health Care, Public-Patient Involvement in Health Research, Community-University Engagement and training needs



Event Report

Date: 18th May 2022

Time: 15h – 17h, CEST

Venue: Magna Room
Historic Building of the University of Barcelona
Gran Via de les Corts Catalanes, 585 · 08007 Barcelona

Context:

From the healthcare perspective, a paradigm shift is taking place and call for **putting the values and priorities of patients first**. The concept of **Patient Experience** has become the third pillar of health care quality, in addition to effectiveness and safety. Therefore, understanding and giving priority to the **XPA is a mandatory action step to achieve patient involvement and people-centred collaborative healthcare**.

At the same time in the health research field, concepts like **Citizen Science or Public and Patient involvement in Health Research** are developing and gaining interest for many stakeholders. These concepts call for a **more open, collaborative and inclusive health research** in order to better respond to society and patient's problems and priorities. Opening up research processes to co create research priorities and projects through an active participation of all the direct stakeholders is a good way to achieve people-centred health research.

Healthcare and health research should not be two areas that work separately and should seek to provide feedback to each other.

This session was therefore articulated around the concept of "**Participation**" in both areas, and will address these different topics and questions:

- What role can play **universities in supporting a more active collaboration with their community**? What is and how has evolved the **concept of Community-University Engagement** these past decades?
- What is **XPA**? How to **evaluate and introduce XPA** within health care to respond to patients and caregivers' priorities and needs? How XPA can help undercover healthcare research priorities for patients?
- What is **Citizen Science / Public & Patient Involvement** in health research? How to **prioritize research according to civil society and patient's needs**? How to **opening up research processes** to make them more porous to society? What kind of **science-society mechanisms** exist to operationalize these types of projects?
- **What legal frameworks could enhance these practices?** The design of the norms referring to the protection and well-being of patients should integrate participatory channels of dialogue beyond actual procedures. Is it necessary to guarantee specific participation of citizens, both collectively and individually? Is it necessary as well to collect their opinions regarding the improvement of the laws?
- What are the **training needs for all actors** to be able to work together in an effective way? how to integrate these into the teaching and research programs?

This session was organized in collaboration with the **UNESCO Chair for Community Based Participatory Research and Social Corporate Responsibility for Higher Education Institutions**. We therefore had the opportunity to learn from **international academics as well as local speakers** highlighting the work developed in the Clinic Public Health Corporation context.

This session was a unique opportunity to hear from **different experiences around of the world**, and **learn together about the benefits and impacts of participatory practices**, both in healthcare and in health research.

Panelist:

Moderator of the session: Anne-Sophie Gresle, Senior Project Manager, Living Lab Hospital Clinic and Barcelona CaixaResearch Living Lab - Barcelona Institute for Global Health.

International Experiences

- Prof George Openjuru, Vice-Chancellor, Gulu University, Uganda.
Prof. Openjuru will give an overview of the development of the idea and the emergence of Community-University Engagement as a concept. He will give some background on how the concept has evolved over the past 30/50 years. He will also present what Gulu University is doing around Health and Community.
- Dr. Rene Oosthuizen, Academic lead, K4C Hub, Rhodes University, South Africa.
Dr. Oosthuizen will talk about their Community-University Engagement department, how they are organized and how they work, what policies in South Africa support their endeavors, and she will illustrate their work explaining what happened during the COVID pandemic, how they worked with the community and with different stakeholders.
- Dr. Alfonso Reyes Alvarado, the Vice Chancellor of the University of Ibagué from Colombia
Dr. Alvarado will talk about how the University of Ibagué has engaged in a continuous community-based research process with undergraduate students to work with communities in small municipalities to tackle social problems in different domains, including health care.

Local Experiences

- Dra. Montserrat Puig Llobet, Vice-Rector for Equality and Gender, Barcelona University.
Dra. Puig Llobet talked about the actions and activities that the University of Barcelona is developing under the SDGs framework, especially in regards with Health, Equity and Participation.
- Dr. Joan Escarrabill, LivingLab Director, Hospital Clinic of Barcelona.
Dr. Escarrabill talked about the concept of Patient Experience, and how the Hospital Clinic, through the work of its LivingLab, is evaluating and implementing patients' needs and priorities for a more people centered healthcare.
- Dr. Michela Bertero, Scientific Director IDIBAPS
Dr. Bertero talked about Open Science and Public & Stakeholder Involvement in biomedical research, in the framework of the European ORION Open Science project. What did we learn? What are we still missing in our context to further develop engagement practices?
- Dr. Elena Lauroba, Full Professor of Civil Law, Department of Private Law, Faculty of Law, Barcelona University.
Prof. Lauroba talked about if and how the design of the norms referring to the protection and well-being of patients should integrate participatory channels of dialogue beyond actual procedures.

This session was addressed to:

- Health professionals
- Health researchers
- Project managers
- Students
- Policy makers
- Civil society organizations
- Patients and caregivers

Notes from the session:

As part of the UNESCO World Conference on Higher Education that took place this week in Barcelona, several experts working on the topic of Participation, applied in different settings such as in Public and Patient Involvement in healthcare and health research or in Community-Universities Engagement activities, held a panel to share their experiences and reflect on ways to enhance the participation of patients, citizens and communities in the field of health. The session offered a unique opportunity to learn how participatory practices in Universities, healthcare and health research are an opportunity to innovate, create social change and tackle complex problems with and for the society and the community.

Experiences of community engagement from Universities in Uganda, Colombia and South Africa showed that Universities, as actors embedded in the community, play a key role in sharing and co-creating knowledge, identifying and addressing the community needs, and creating connections for a transformative impact. *"There is a massive society movement in most towns in South Africa. Any problems or issues quickly gets to the University"* (Prof. Rene Oosthuizen, Rhodes University).

Public Involvement in healthcare and research also offers the opportunity to work out of the box, by integrating the perspectives of the patients, to identify new needs and approach them differently: *"A deliberative model based on participation is crucial to address the real world and complex problems that we may encounter at the Hospital"*. (Dr. Joan Escarrabill, Barcelona Hospital Clínic).

Dr. Rene Oosthuizen spoke of institutionalising CUE at Rhodes University and the integral role of communities and Multi stakeholder partnership to find health solutions during COVID19. Dr. David Monk spoke of Gulu Hub and its foundations in social justice. CBPR is done holistically in fields such as herbal medicine - elders come and share their recipes of knowledge. They also share ideas about preserving biodiversity. Dr. Alfonso Reyes Alvarado from Colombia spoke of how his university has become an institutional catalyst for local transformation. Through this personal growth of students, including local capacities of municipalities and social responsibility of university are ensured.

Citizen science and patient participation generate a growing interest in the scientific community, and there is a great need to make more visible this type of approach and most importantly its benefits. Paying attention to the needs of patients and of society is fundamental, to change perspectives and address the needs of the community to achieve a long-lasting and sustainable impacts.

The conference was organized in collaboration with the UNESCO Chair for Community Based Participatory Research and Social Corporate Responsibility for Higher Education Institutions

and with the support of the University of Barcelona, Hospital Clínic and Barcelona Institute for Global Health (ISGlobal). *It is the result of many years of cooperation and commitment towards Public and Patient Involvement at Hospital Clinic and ISGlobal, Anne-Sophie Gresle).*