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## CONFERENCE ABSTRACT

### **Involving patients in research funding schemes for more relevant patients' outcomes**

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Maha Ganem<sup>1</sup>

1: Clara, Bourgoin-jallieu, France

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While the involvement of patients in research is gaining momentum through participatory and community research projects, few experiences report on the involvement of patients ahead of these projects, i.e. in the development of research funding mechanisms and the co-design of research questions. This phase is however of primary importance, since it is within it that the disciplines, themes, or even type of research (fundamental research, translational research, interventional research, etc.) eligible for funding are defined. Patients, caregivers and their loved ones are essential partners in research as "patients ask new scientific questions, reflect on the organization of research and the interpretation of results" (Towards good research practices participatory research, note from GRAM, INSERM, March 2022). It is then necessary to reflect on their involvement at all levels of the "research system" as we try to do in the healthcare system.

Our oral paper aims precisely at sharing the experience of collaboration of the Cancéropôle Lyon Auvergne-Rhône-Alpes (CLARA) with patients grouped together within a dedicated working group named ÉCLAIR (lightning). Established in 2001 through a regional initiative, the Cancéropôle CLARA is a public regional institutions that brings together academic researchers, clinicians and industrialists from the Auvergne Rhône-Alpes region in France. As part of the French 2003 national cancer plan, CLARA serves the regional, national and international strategy in the fight against cancer.

The patient-led working group met for the first time in December 2020, its main objective was to design and co-manage a call for research projects named "Themed OncoStarter 2021", i.e. to write the specifications, develop the expertise grid, select the winning projects, award the money and monitor the progress of the selected projects during their year of funding.

In our presentation we will highlight two main dimensions: on the one hand, we will present the organisational methods of the group, that is to say explaining concretely how the group was formed and how its members work together and with the Cancéropôle. On the other hand, the communication will outline the choices made by the group in the design of the call for projects and will offer feedback by comparing the work carried out for the 2021 OncoStarter call and for the 2022 call.

We will complete our discussion by taking a step back from this process, which is still in progress, and describe the context in which it was initiated. The involvement of patients at CLARA started back in 2017, when a patient, Raymond Merle joined its Scientific Steering Committee. Since then Mr Merle obtained his doctorate in Educational Sciences and created the Patients department

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within the school of Medicine & Pharmacy at University Grenoble Alpes. Today, CLARA is developing a partnership with that same Patients department. Finally, we will detail how and why the working group decided to reflect on how it operates and to adopt a charter that was validated by CLARA's board of Directors in September 2022