POSTER ABSTRACT

Patient involvement strategies to improve the quality of cancer care and research

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Introduction: Quality improvement in cancer care and research is a major goal shared by healthcare professionals, researchers, patients and the public. Recently, the Organization of European Cancer Institutes (OECI), which promotes the concepts of comprehensiveness and multidisciplinarity for cancer centres, has produced a framework with the European Cancer Patients Coalition. This framework engages institutions to improve quality through the involvement of patients and the collaborations with local and national patient organisations. In order to examine how European cancer centers build their own models of patient involvement, a survey was designed: 1) to assess the level and variety of the patient involvement activity; 2) to describe the relationships between institutions and patient organisations; 3) and to map the best practices in term of patient involvement and collaborations.

Methods: With 17 questions, the survey explores how cancer centers involve patients and their relatives, and how collaborations with patient organizations are settled. The survey was conducted online in May 2018; the questionnaire was sent, specifically, to the personnel in charge of patient relations of all OECI cancer centres: 76 institutions, as of January 2018.

Results: With a response rate of 78%, the results first show that the level of patient involvement is high in OECI cancer centres. Indeed, 81% of the centres (n=48) state that they involve patients in the design of services (like the support to patients, the organization of care or the improvement of administrative processes) and in the improvement of research. However, only 25% of cancer centres (n=12) declare having set up indicators of performance to assess the impact of patient involvement in their projects. Second, almost all centres involving patients claim that they collaborate with patient organisations (98%). Third, best practices in term of patient involvement and collaborations with patient organizations were documented by 43 of the respondents (73%) providing detailed information on specific initiatives carried on in their centres.

Discussion: The large participation of OECI cancer centres in the online survey shows a strong activity and willingness to share on the survey’s topics. Patient involvement and collaboration with patient organizations seem to be widely adopted in the centres in very diverse areas of care and research. However, the lack of specific indicators for performance may also show that the patient involvement activity is still at its premises.
Conclusion: On the basis of the survey results, it might be concluded that the model of comprehensiveness and multidisciplinarity promoted by the OECI already incorporates a strong patient involvement component, and that collaborations with patient organizations are already in place. A more rigorous assessment of the patient involvement activity should be set-up in order to get more benefit of the initiatives. However, such successful experiences of collaborations between patients and professionals can illustrate how capacities of patients can contribute to change practices.

Limitations: This research has some limitations: 1) the results are based on self-assessments; 2) the OECI is a specific group of cancer centres which share several common norms and practices in term of quality management.

Keywords: Patient; strategies; improve; quality of cancer;