

EPF Congress report¹ :

The [European Patient Forum](#) (EPF) congress was held in Brussels from 12-14 November 2019. The congress focused on PPI (public and patient involvement) in research, care and medical training.

Speakers were patient representatives, physicians, policy makers, scientific journal editors and scientists. Michel Ballieu represented the [Biomed Alliance](#), of which ESICM is part.

The notion of the patient as a partner in his/her care has been discussed for over a decade, but is not implemented at all levels. At a political level, especially at the European Commission, the experience and voice of patients has an increasingly important place, whereas in the medical practice, it is often difficult to assess how and when to involve patients.

Healthcare systems are complex and designed for professionals and rarely for or with the user of the services. It was suggested at the congress that involving patients and citizens with the various stakeholders could help create more efficient health systems, answering unmet needs and reducing unnecessary costs.

The congress highlighted that healthcare systems have evolved towards fees by act and reduced costs. Nevertheless, reducing costs - by limiting the number of beds or healthcare professionals - also limits the time spent by physicians or other healthcare professionals with their patients and effective communication.

To improve healthcare systems, patients and citizens need to be involved at various level and their experience can help design better care and better prevention programmes adapted to their actual needs.

In some hospitals, patients are involved in ethical committees or in the development of medical studies curriculum. At first, it might seem counter-intuitive, but the experience of the University of Montreal (among others) has demonstrated genuine enthusiasm of doctors and patients to collaborate. Students have enjoyed the lectures from patients and doctors and felt that content of their curriculum was enriched with the input of patients. The doctors involved patient representative from associations or regular patients from their practices.

The Biomedical Alliance has recently included patients in its Continuous Medical Education (CME) Committee and EPF is a permanent representative on this Committee. On the other hand, European Medicines Agency (EMA) has been involving patients for some time and finds they add value by helping identify unmet needs in the population. Patients also help re-shape regulatory aspects. The British Medical Journal (BMJ) also uses patients and citizens as editors and emphasises the need for patients' involvement to their submitting authors. They also have a lay review board.

It was suggested at the congress to create and use more often quality of life parameters and patients' outcomes as metrics, not only for clinical trials, but also during routine practices. Moreover, to create better metrics and parameters that are sensitive to actual/unmet needs of patients, quality of care from the patient's perspective, as well as these, could also make analysis that more accurately addresses the efficiency and effectiveness of a health systems. Indeed, it was mentioned that even countries such as France or Belgium which enjoy high quality care and resources show a high level of unmet needs and quality of life is rarely in the equation.

Where research is concerned, it was suggested to involve patients from the start in the selection process of the research question and the study design, to ensure that the relevant question is asked,

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thus enabling an improvement of the healthcare systems. This does not mean that patients have to be part of all processes, but that they should participate, to help the focus of the research.

One issue was raised in terms of involved and visible patient population: often marginalized groups are not part of patients' organisation or involved in discussion, although they are the most in need. The necessity to reach these communities and increase the time for exchange was highlighted.