



Patient engagement as a crucial asset of preclinical biomedical research

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In the last 10 years there has been an exponential increase of scholarly publications discussing the value of engaging patients in healthcare and biomedical research. The concept of engagement refers to a process by which people are enabled to become actively and genuinely involved in defining relevant issues in their care, in making decisions about factors that affect their lives, in designing and implementing policies, in planning, developing, and delivering services, and in taking action to active behavioural and life style change (WHO, 1992). Within the scientific debate, patient engagement is frequently related to individuals' healthcare behaviours (ie, adherence to treatment, self-management, proactive preventive behaviours, [7]; Finset et al., 2017), and attitudes towards the change of health behaviours or the adoption of a treatment [5]. However, a growing body of international studies have advocated for including taking patient input along the biomedical research process to enable a more ethical process of innovation and to guarantee a larger acceptancy of resulting innovations by its potential patient target. Patient engagement in the process of drug development or in health technology assessment [3,8], from this perspective, have been demonstrated promising to improve the effectiveness and applicability of the results achieved in the research process.

In this issue of EBioMedicine, Fox and colleagues [4] present the results of a Scoping Review aimed at mapping and synthesizing current patient engagement practices in preclinical laboratory research. The study demonstrates that, although at its infancy, there is a growing effort in preclinical laboratory research to involve patients in the co-creative process of defining aims and scope of the research itself. The main experiences of patient inclusion – according to the practices retrieved in this scoping review – are related to the initial phase of research priorities setting, resulting in an improvement of the mutual understanding between researchers and patients along the study endeavour. This also boosts the sense of collaboration and reciprocal learning within the research team.

Although preliminary, this study confirms the potentialities of engaging patients in biomedical research: not only as a methodological practice for improving the study's innovative impact, but also as an asset for guaranteeing the climate of trust in science and smoothing future obstacles towards the adoption of scientific results. Thanks to the early involvement of patients in the research process, biomedical scientists can gain a concrete understanding of the worries and the expectations of their target patient population: this is the basis for increasing the disrupting acumen of their study and endorsing researchers' ethical sensitiveness, particularly when debated issues are concerned.

However, if certainly promising, the process of patient engagement in preclinical biomedical research is extremely complex and cannot be improvised. Crucial barriers to patient engagement in preclinical biomedical research are related to both psychological (eg, inability to cope with the disease, distressing emotions, cognitive impairment, low disease awareness, [6]) and sociological (eg, in terms to equity in the care access, gender and cultural differences in the approach to healthcare; [9]) factors related to the patients. At the same time cultural, organizational and political factors (eg, the organizational culture of the health provider, and institutional biases, [1,2]) can hinder the ability of biomedical scientists to achieve a meaningful engagement of patients in their preclinical research.

However, it is important questioning the methodological requirements for ensuring a reliable and rigorous engagement of patients in preclinical biomedical research. Psycho-social scientists in the last decades have developed useful evidences and methodological guidance for designing and conducting rigorous participatory research involving patients. Settings, phases, and processes involved in such methods should be carefully handled when embracing patient engagement in preclinical biomedical research, to avoid a tokenistic approach. Special attention should be paid to the issue of representativeness when sampling the patients to be engaged in the research project itself. In this regards, careful attention should be paid to the levels of patient engagement of the individuals involved in the research process. Patient engagement should be systematically measured across clinical settings and time-frames in order to cluster patient attitudes towards their involvement in research process: this may guarantee that a diverse spectrum of patient experience is taken into consideration in the definition of research expectations and priorities. A broad corpus of previous research has demonstrated how the measurement of patient engagement levels can constitute an important strategy to sustain collaborative and co-creative research

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process, guaranteeing equity of access to the research process and to the innovation achieved.

Measuring the levels of patient engagement can unveil the specific psycho-social characteristics of different patient targets, casting light on their requirements for the process of innovation, and suggesting key cues for orienting communicative strategies to sustain their full participation along the whole process of research development.

Furthermore, the measurement of the patient engagement level can sustain the psychological fine-tuning between researchers and patients along the process of research, nurturing mutual understanding and science trust: all crucial ingredients for a successful innovation and its full acceptance in society.

Contributors

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Declaration of Competing Interest

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