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Editorial

Patient's Involvement, Engagement, and Participation in Medical Research: Nepalese Perspective

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Research plays an integral role in evidence-based patient management. Traditionally, patients have a role as “passive” members in healthcare as well as in research. Those research where the patient does not have active participation were believed to be prone to unethical conduct.¹ There is changing paradigm of research “to”, “about” or “for” patients to research “with” or “by” patients, potential patients, care providers, and who use health services.² Currently patients are active partners in research with their roles and responsibility increasingly defined.¹ Patient involvement can be done by discussing research design, disseminating of key research findings, and increasing awareness of research, which is critical in patient engagement.² These activities increase retention of participants in the trials as well as help to identify uncovered research ideas.^{3,4} To facilitate these steps, specific guidelines are laid by various authors and organizations on how to actively involve, engage and participate patient in the research before, during and after the study.⁴ These research activities involving patients have started in developed countries. However, there are huge challenges in the execution of these concepts in many parts of the world due to the “educational and societal gap” between the investigators and study participants.⁵ Additional are lack of funding, level of understanding by patients, poor administrative arrangements, and absence of open discussions between researcher and patients are various issues for its implementation.⁶

Patient involvement, engagement, and participation in medical and public health research is a new concept in developing countries.⁷ Nepal is taking a new step in research areas with the introduction of various clinical trials in clinical medicine and public health in collaboration with various national and international institutions in the post covid era. In the past, there was very little interaction between researchers and patients in developing countries including Nepal. Even if there were patient participation, it was only at the planning stage.⁷ Therefore, this is the right time to act to integrate the patients as active partners in our research. We have to disseminate the importance of active patient participation to young researchers. Topics on good clinical and research practice at medical schools as well as regular training for young researchers help to motivate to implement these activities. We also have to create patient groups that will help to communicate with researchers to share their experience of the research process and also provide participant feedback that will help in future research. There is an immense role of the ethical review boards and institutional support to facilitate this process that will ultimately help the researcher, patient and scientific community.

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