

Lived experience in research and publishing

Deniz Ceylan¹

¹Assoc. Prof., Koc University, Department of Psychiatry, Istanbul, Turkey
<https://orcid.org/0000-0002-1438-8240>

Lived experience encompasses the unique personal perspectives and encounters individuals have based on their own lives, including various situations, challenges, and conditions. In the context of mental health, lived experience involves an individual's journey with mental health and illness, including the process of recovery, as well as the experiences of those close to them. Active participation from individuals with lived experiences, including individuals with psychiatric disorders and their close acquaintances, is essential for psychiatric research. However, traditionally, their involvement has been restricted to the clinical patient recruitment phase of trials. Recently, there has been a growing emphasis on integrating lived experiences across various facets of mental health research.

Engagement of individuals with lived experience goes beyond merely participating in clinical studies as study subjects. It involves activities such as making plans, finding financial support, and validating the accuracy of data. As a pioneering initiative in this innovative approach, INVOLVE was established in 1996 and is part of, and funded by, the National Institute for Health Research to support active public involvement in healthcare and research (1). Canada's Strategy for Patient-Oriented Research (SPOR), initiated in 2009, places patients and their families at the center of health research (2). In the United States, the Patient-Centered Outcomes Research Institute (PCORI), founded in 2010, actively engages patients and various stakeholders in all aspects of research ensuring that studies funded by PCORI specifically address questions most relevant to patients and are crafted with their input (3). Consequently, a substantial amount of literature

demonstrates that genuinely involving individuals with lived experiences can enhance the quality and efficiency of health research. This shift marks a fresh approach, redefining the role of individuals with lived experience from being research subjects to actively contributing members of the research team. With guidance from lived experiences, there is potential to approach research in a more inclusive, collaborative, and patient-centered manner.

An increasing number of funding organizations now compensate reviewers with lived experience. Recommendations and guidelines are now available, outlining how to incorporate and provide educational support for individuals based on their lived experiences (4,5). This practice ensures that study ideas and research proposals resonate with individuals who have personally experienced or witnessed the illness under investigation. PCORI involves patients, caregivers, advocates, alongside stakeholders and scientists in the peer review process for final research reports (3). In the mental health context, the federal agency Substance Abuse and Mental Health Services Administration emphasizes that individuals with lived experience and/or their family members should actively participate in the design and implementation of all data and program evaluation activities (6). European funding organizations dedicated to neuroscience and mental health research also rely on the insights of reviewers with lived experiences associated with mental health (7,8). These reviewers evaluate elements such as patient engagement, feasibility, and the overall relevance of research proposals. This engagement not only enhances the quality and relevance of research but also promotes patient-centered care, empowering individuals to take an

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active role in managing their health.

Active involvement of individuals with lived experiences in mental health research also involves roles in academic publishing. Several academic journals, such as the *Lancet Psychiatry* (9), *Schizophrenia Bulletin* (10,11), publish narratives that draw from lived experiences. Notably, these narratives may also feature insights from mental health care providers who themselves have lived experiences, providing a unique and valuable perspective within the academic discourse (12). Moreover, individuals with lived experience have been taking on leading or coauthoring roles in scholarly publications and participating in the peer review process for academic journals. As an innovative journal, *BMJ Involvement and Engagement* for almost 10 years. This journal ensures that each article undergoes review by a minimum of two academic reviewers and two patient reviewers, with both types of reviews carrying equal weight in the editorial decision-making process (13). In 2017, *Research Involvement and Engagement*, in collaboration with *The BMJ*, conducted an investigation into the thoughts and motivations of patients who participated in peer review for these two journals (14). Recently, *Lancet Psychiatry* has started lived experience peer-review. Lived experience is also incorporated into the International Advisory Board of *Lancet Psychiatry*, where board members provide advice on the journal's subject matter, academic content, geographical considerations, and lived experience on an ad hoc basis, responding to requests from the editorial team (15).

Integrating lived experiences into the peer-review process has the potential to bring about significant changes in both mental health publishing and research. This approach involves using plain language and concepts that are more accessible and less specific to services. Consequently, this shift makes research more acceptable to a broader range of service users, enlarging the pool of readers and increasing the likelihood that individuals with

mental health experiences can comprehend and engage in mental health research. Of utmost importance, researchers stand to gain more effective insights by adopting a non-stigmatized language with the help of reviews from individuals with lived experiences. Academic journals that have embraced patient peer review early on are already committed to prioritizing person-centered language in publicly available abstracts and emphasizing translational and practical research.

When considering the context of Turkey, research funding organizations, such as the Scientific and Technological Research Institution of Turkey (TUBITAK) and Health Institutes of Turkey (TUSEB), and mental health journals can gain valuable insights from lived experiences. Health literacy and language may present challenges for such initiatives in Turkey. Several circumstances in Turkey, such as economic shortages and limited funding, create challenges in research and publishing. On the flip side, there are noteworthy resources, including an experienced psychiatry community and well-developed academic journals. More importantly, the presence of advocacy organizations, including individuals with lived experiences such as the Schizophrenia Associations Confederation, Lithium Association, and Bipolar Life Association, holds future potential for providing a considerable source for this perspective. This novel viewpoint has the potential to enhance research and publishing processes in our country, leading to a restructuring of the research culture and the utilization of resources in accordance with genuine needs.

Correspondence address: Assoc. Prof., Deniz Ceylan, Koc University, Department of Psychiatry, Istanbul, Turkey
denizceylandr@gmail.com

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