

Inclusion in neurological research: empowering people living with neurological diseases

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Abstract

The value of involving people living with diseases in the research process is increasingly recognized by professional associations and regulatory agencies alike. Patient contributions range from disease prevention and diagnosis to medication planning, and from advocacy to guideline production and clinical trial design. Thanks to the efforts of activists and advocates, new models of patient inclusion in medical research are being developed to replace outdated non-participative and tokenistic paradigms. New modalities of patient participation in research — for example, the introduction of patient experts, who work closely with researchers and clinicians — have progressively empowered individuals who are living with diseases. In this Perspective, we provide an overview of the current status of patient involvement in medical research, with a specific focus on neurology. We also discuss the existing and future roles of patient experts in neurological research.

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