

We need to engage representative patients' community rather than 'expert patients' to increase impact of research in the era of personalized medicine – Commentary

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As patient-advocacy representative, with experience in neuroscience research in different sectors (academia, pharma, and a patient organization), I have had the privilege to face the challenge of maximizing the impact of patients' engagement in brain health research from different perspectives. An increased patient engagement in brain health research is becoming a scientific, in addition to a social, need for our community. There is indeed the need to give content of validity to a renewed concept of value, of humanism, from research to care. In the words of the European Commission (EC), several key aspects indeed call for a patient engagement strategy, in line with the Responsible Research Innovation (RRI) principles of the EC.¹ We need to invest in a brain health research agenda² that will support a paradigm shift towards preventive and personalized medicine and 'personal value' needs to be at the core of the value-based healthcare decision-making approach.³ Moreover, digital- and neuro-technologies can be the method at the service of this paradigm shift, if people living with the disease and their caregivers will be engaged at all steps of Research and Innovation.⁴ An increased patient engagement in registries and data base generation can fast track us towards an effective data circulation across European Health Data Space and beyond, by also advocating for the right balance between the individual's right to data privacy and scientific innovation. Neuro-ethics can serve to anticipate and address ethical questions raised by brain health research and citizens and patients perspectives are instrumental to identify these questions. Meeting the above challenges, the two opposing views published in this issue of the MSJ discuss whether we need to engage representative patients' community rather than 'expert patients' to increase impact of brain health research. On the 'YES' side of this controversy, Drs Usman Khan focus on the need for patients to support the delivery of personalized

medicine, discussing that it is the representative patient community that best aligns to the aims and objectives of the era of personalisation. The reality for improving the impact of clinical research is more on our ability to enable a targeted approach via an accurate stratification of the patient population. One size does not fit all: guarantee a good representativeness of patients engaged in research means guarantee equal access to all the different illness experiences, which is instrumental to identify distinct group of people living with the disease. Capturing people experiential knowledge early in the disease will also provide insight into the 'hidden' parts of multiple sclerosis, uncovering progression, to enable the holistic approach needed to prevent disease progression.⁵ On the 'NO' side, Drs Alberto Gajofatto and Drs Michela Rimondini mostly focus on providing evidence that both expert patients and representative patients' communities play important roles in healthcare and research. The author claims that the specialized knowledge, advocacy skills, and ability of expert patients can bridge the gap between science and the broader patient community. However, bridging the gap between science and the broader patient community should be a multi-stakeholder responsibility and should not delegate to expert patients. What began as an extension of advocacy that led to the 'expert patients' approach must now evolve in the new discipline: the science with and of patient input. The definition of this new science comes from the RRI EU MULTI-ACT project.⁶ The MULTI-ACT model has the potential to enable institutional changes for applying multi-stakeholder participatory governance in patient engagement in health research. In this model, people living with the disease real value towards preventive and personalized medicine is not their specialized knowledge, advocacy skills, but their expertise in sharing their experiential knowledge from research to care.^{7,8} Shifting away from relying

Multiple Sclerosis Journal

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DOI: 10.1177/
13524585251315364

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on expert patients and working towards science with and of patient input is becoming a responsibility shared by relevant stakeholders and initiatives.^{9,10}

Data Availability Statement

The research data available is not applicable to this manuscript.


Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) received no financial support for the research, authorship, and/or publication of this article.

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