prospective or cross-sectional studies focussing on neuropsychiatric manifestations in SLE, defined according the ACR criteria of 1999. Study selection and data extraction was made in duplicate. We secured salient study characteristics, composition of cohorts, the definitions and the frequencies of neuropsychiatric manifestations. We assessed heterogeneity across reports and investigated sources of variation using meta-regression models. 

Results The frequencies of severe manifestations found in the SSLE were 7.1% (49/688) for cerebrovascular events, 5.3% (37/688) for seizures and 6.5% (45/688) for psychosis. The time-to-event analysis showed a linear relationship between duration of SLE and cumulative incidence of severe neuropsychiatric manifestations. Searches identified 530 studies and authors’ contact yielded another unpublished report. We included 28 studies. The mean rates of the most commonly reported severe neuropsychiatric manifestations ranged in the magnitude of 50 percent points. Study characteristics and composition of cohorts could not explain heterogeneity of reported manifestation rates.

Conclusions The spectrum of neuropsychiatric manifestations in SLE is widely dispersed. The diagnostic work-up and the reporting of manifestations varied substantially across studies which may explain inconsistencies to some extent. We call for concerted efforts and a broad consensus regarding stringent definitions of neuropsychiatric SLE manifestations that allow targeted detection, particularly with view to timely intervention and patient outcomes.

Background Patients involvement has massively changed over the years. From patients as ‘objects’ of care, we have moved to patient centric approaches and are now embarking at full speed in the era of patients as partners. To better meet this evolution, a radical change is taking place in Patient organisation. LUPUS EUROPE is one of the leading players.

Methods We have stepped up our capacity and capability by creating a Patient Advisory Network, organising ‘naïve’ patient panels - by and for lupus people; and running surveys in the community.

Results Our Patient Advisory Network now comprises 18 patients that are investing time and effort to develop their knowledge and to help academics, investigators, industry and other partners. They are currently engaged in more than 20 different projects. We are active in the ERN ReCONNET, EURORDIS and EJP RD. Our patient panels have already addressed the topics of: defining treatment; adherence; clinical trials and youth. Our latest research, on Hydroxychloroquine, obtained 3500 answers from all over Europe. Thanks to this stepped-up capability, we are now also ready to work with EMA, as an EMA eligible entity.

Conclusions Lupus Europe is ready to partner where it can add value, and to receive requests for support from researchers. In 2020 again, we will launch significant initiatives in the research area: A large scale survey on ‘living with lupus in 2020’; the collection of feedback from participants in clinical trials to see how we can improve them and increase participation; and a further stepping up of the skills of our Patient Advisory Network. We need your help to increase our reach and work on jointly beneficial projects.

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