

Thursday

The PPA Platform: A unique knowledge translation tool on PPA

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State of the art: Very limited web-based information is available for patients and families affected by Primary Progressive Aphasia (PPA). When accessible, it is often incomplete or worded in complex terminology. One of the objectives of the Research Chair on PPA – Fondation de la famille Lemaire (app-ffl.ulaval.ca) is to educate the general population and healthcare professionals on PPA to promote earlier diagnosis and better care. We present the development of the PPA Platform, an innovative knowledge transfer tool.

Methodology: We carried out a focus group with patients and their relatives to understand their needs. We developed templates for ‘Patients/Relatives’ and ‘Health Professionals’ and adapted content and terminology for both. Content was then validated with experts in the field (neurologists, SLP). Videos were selected to illustrate the symptoms (eg., naming, repetition, etc.) and we included testimonials to further capture caregivers’ experience (eg., first symptoms, challenges, etc.). The French version of the platform was launched in 2020 and the English in 2022.

Results: Since its inauguration, the PPA Platform has been consulted by more than 16 000 individuals in over 85 countries. Moreover, its content has been presented to approximately 500 healthcare professionals over training sessions either in person or by videoconference. Content is regularly updated and translation in other languages (Mandarin, Hindi, Spanish, Arabic and German) is ongoing.

Conclusion: The PPA Platform is an outstanding knowledge translation tool for patients, families and healthcare professionals. In a short amount of time, it positioned itself worldwide as a key reference on PPA.

Conflicts of interest

The authors report no conflict of interest.