

Data-sharing practices among researchers in Alzheimer’s Disease and Related Dementias

Findings from a WYLD global survey



Clarens MF.¹, Fernandez R. ², Arruabarrena, M.¹, Caitlin P. McHugh³, Matthew H. S. Clement³, Crivelli L..¹, Llibre-Guerra, J.⁴

- 1. Department of Cognitive Neurology, Fleni, Buenos Aires, Argentina.
- 2. Institute for Physiology, Molecular Biology and Neurosciences (IFIBYNE CONICET-UBA), Buenos Aires, Argentina.
- 3.AD Data Initiative,, Kirkland,Washington, USA
- 4. Washington University in St Louis, St Louis, MO, USA.

TAKE HOME MESSAGE: Data sharing is highly valued among ADRD researchers, yet significant barriers persist , particularly for ECRs and researchers in LMICs. Targeted, equity-oriented solutions are needed.

BACKGROUND

- Data sharing is essential for accelerating discovery and treatment development in ADRD.
- Despite its potential, significant barriers persist.
- These barriers disproportionately affect early-career researchers (ECRs) and are likely intensified by regional disparities between High-Income Countries (HICs) and Low- and Middle-Income Countries (LMICs)

OBJECTIVE

To identify the barriers and facilitators to data sharing from ECRs across different regions.

METHODS

A cross-sectional survey was developed following an iterative process (Figure 1). Participants were categorized by country income level (World Bank FY2026) and compared across HICs and LMICs. Barriers and incentives were explored across three thematic dimensions (Figure 4)

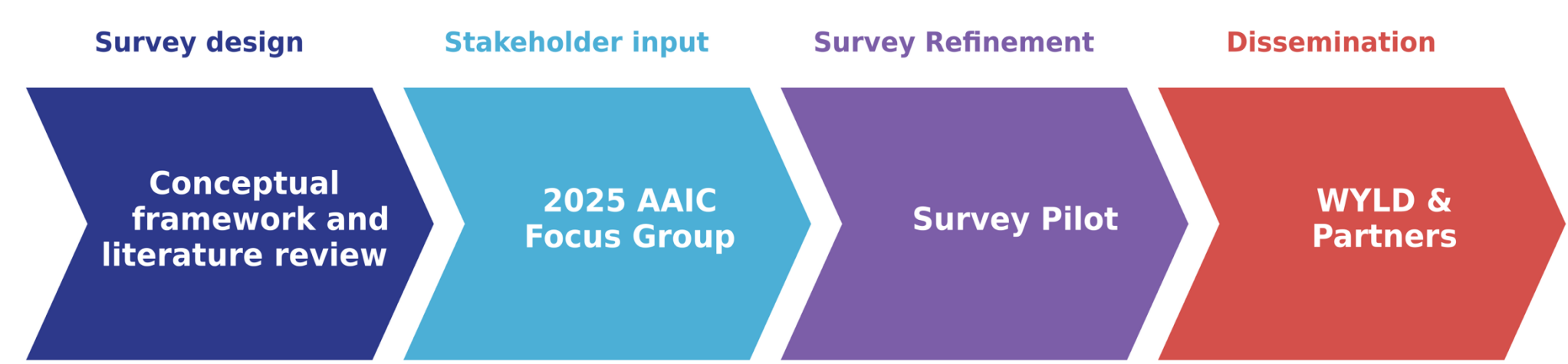


Figure 1. Iterative process for survey development and dissemination.

SURVEY PARTICIPATION

To collaborate in the dissemination of the survey and data collection please scan this code. It takes 15 minutes to Complete and it’s anonymous.



RESULTS

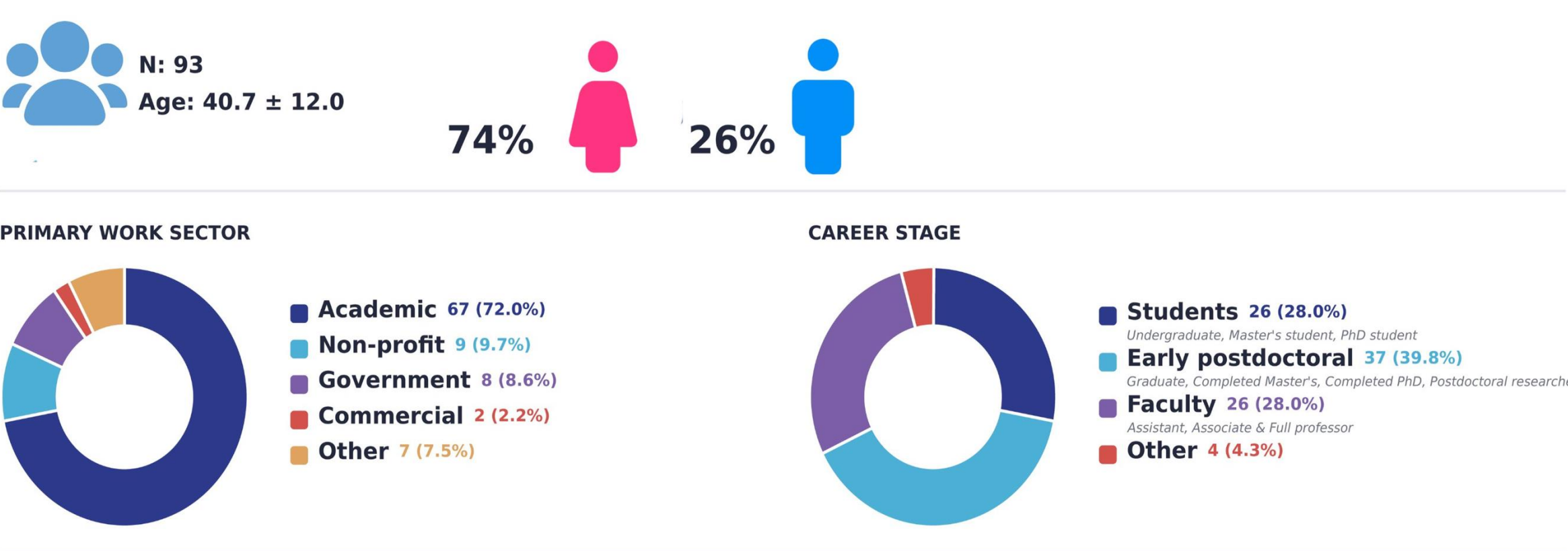


Figure 2. Demographic and academic profile of survey respondents.

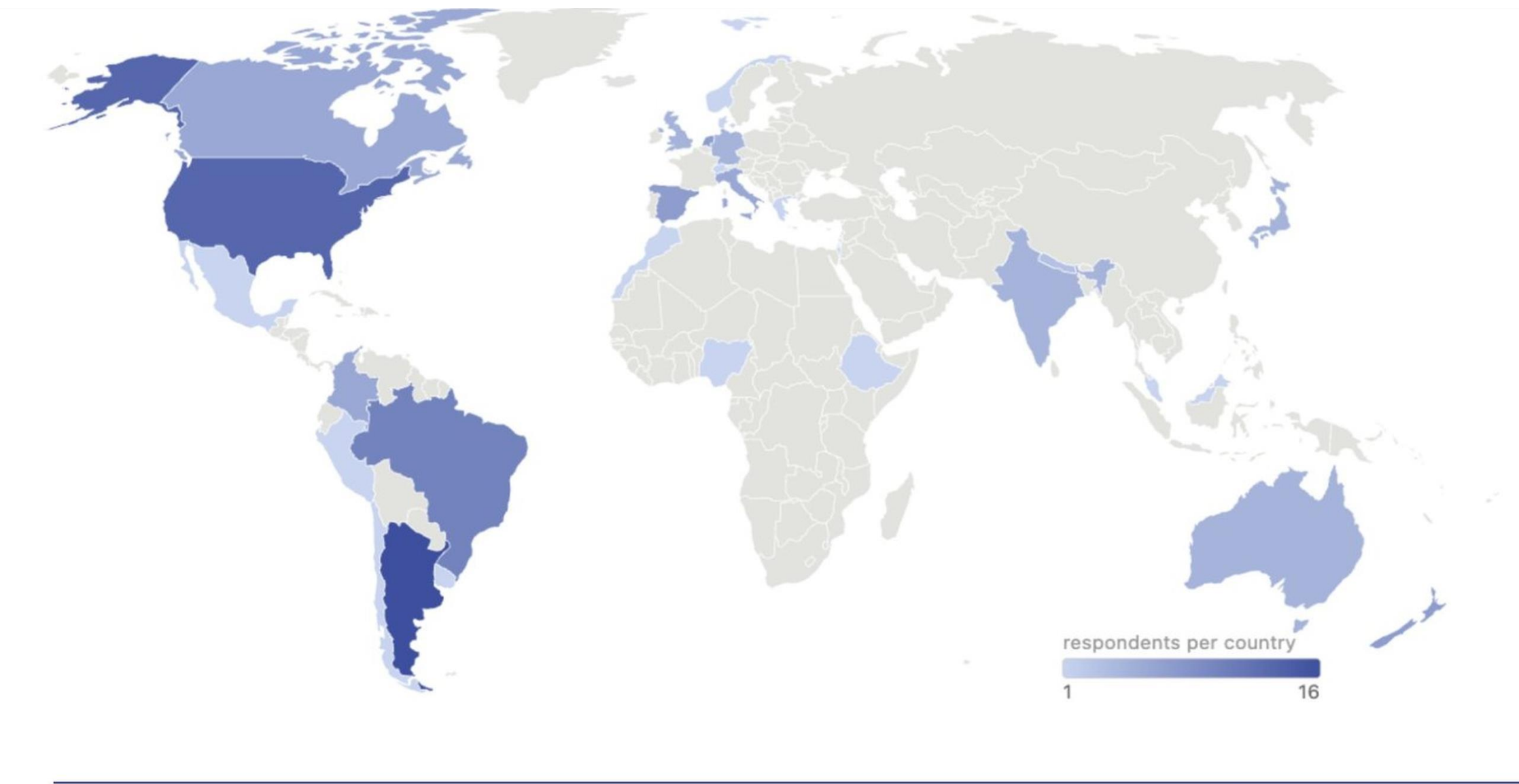


Figure 3. Geographic distribution of ADRD data-sharing survey respondents across 27 countries.

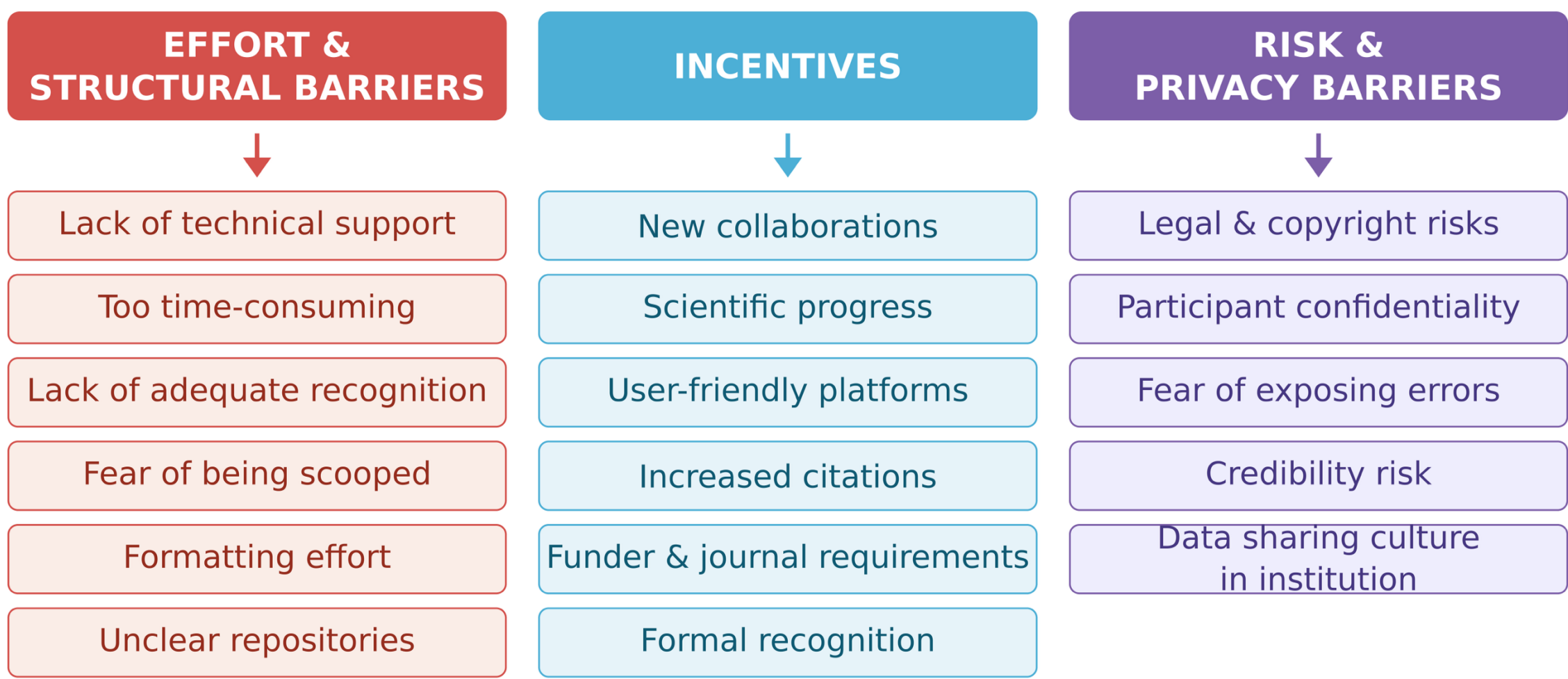


Figure 4. Three thematic dimensions of data-sharing barriers and incentives.

ATTITUDE-BEHAVIOUR GAP

Despite **88.4%** of respondents rating data sharing as highly important, only **19.4%** reported sharing data frequently.

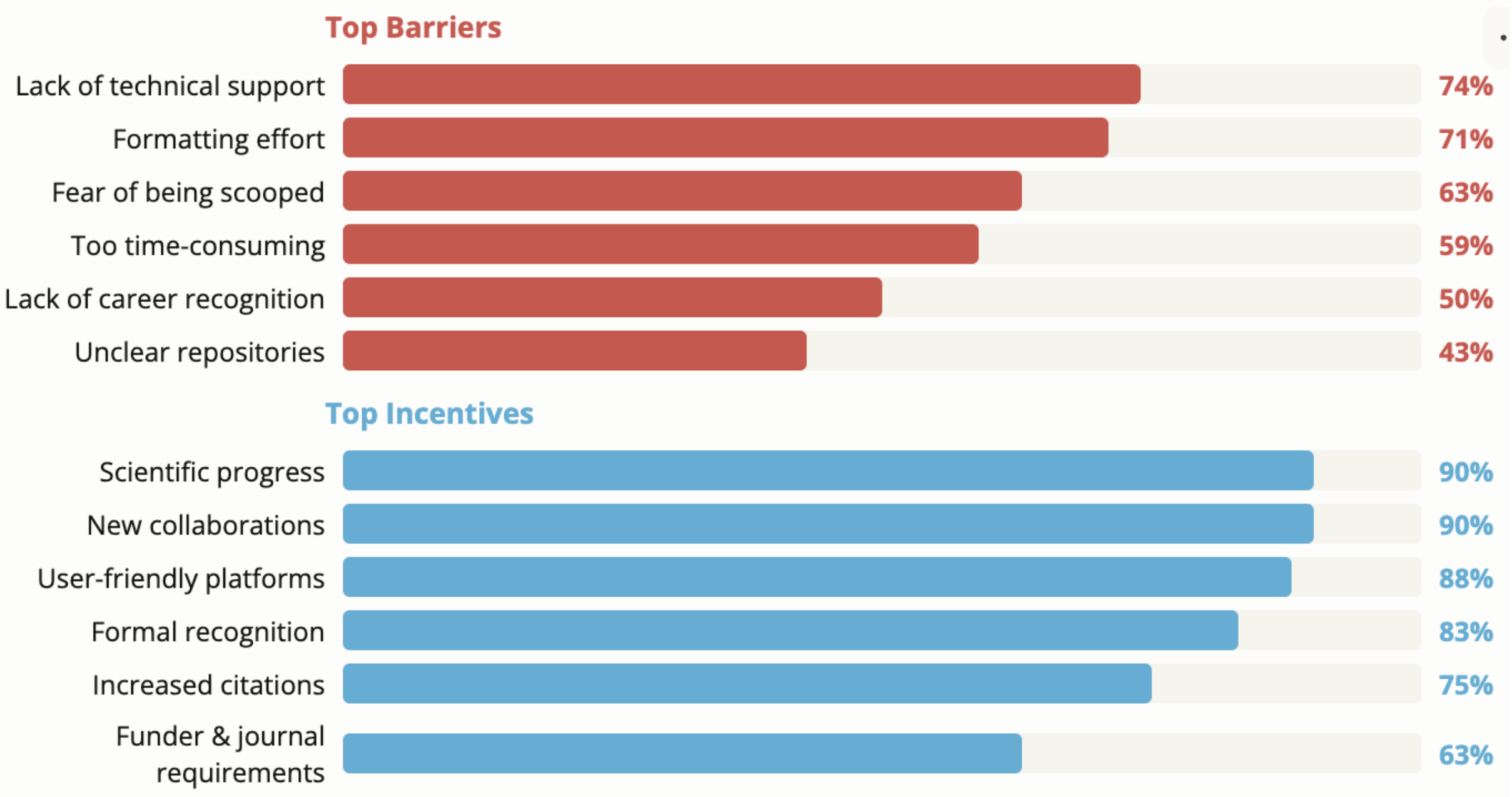


Figure 5. Top barriers and incentives to data sharing among ADRD researchers.

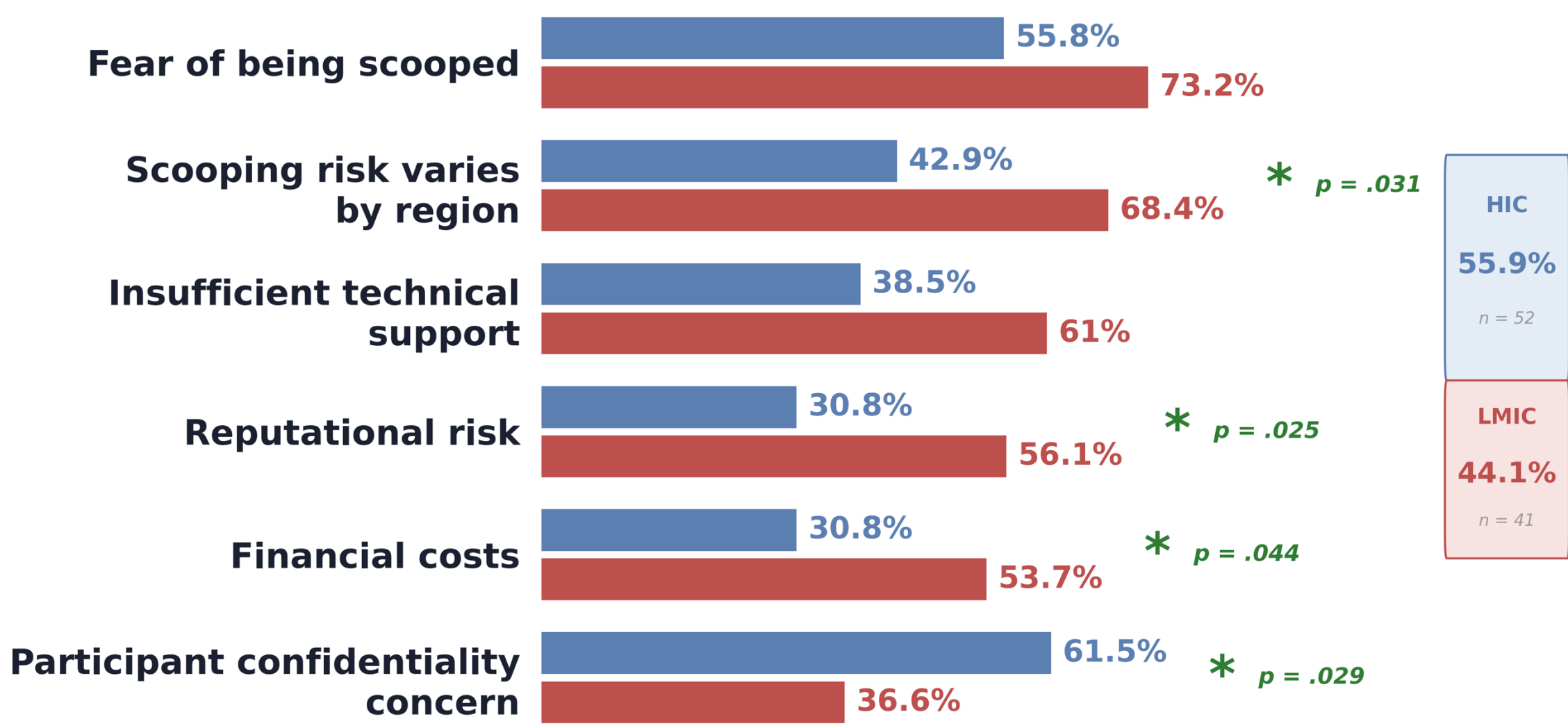


Figure 6. Differences in data-sharing barriers and practices by country income (HIC vs LMIC).

* p < .05, chi-square / Fisher's exact test

CONCLUSIONS

An **attitude-behavior gap** suggests that researchers value data sharing although they don't share frequently.

Three latent domains underlying data-sharing barriers and incentives were identified, informing domain-specific interventions.

Regional disparities in perceived barriers were observed between HIC and LMIC researchers, highlighting the need for equity-oriented solutions.

CONTACT

Corresponding Author
María Florencia Clarens

Department of Cognitive Neurology,
Fleni, Buenos Aires, Argentina

fclarens@fleni.org.ar