



Co-development Of An International Primary Progressive Aphasia Awareness Campaign: Enhancing Understanding Of Speech & Language Therapy

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What is the problem?

People with Primary Progressive Aphasia (PPA) are often referred too late to benefit from speech and language therapy – UK (Volkmer et al, 2020), Italy (Battiste et al, 2022); Australia (Taylor et al, 2009); the USA (Mooney et al, 2018) and Turkey (Can, 2024)

Referrers are often unaware of the role of speech and language therapists with people with PPA (Volkmer et al, 2020; Volkmer et al, 2019; Gallee et al 2024)

People affected by PPA report a lack of knowledge of the role of the speech and language therapist in PPA (Loizidou et al, 2023)

What can awareness days achieve?

- Dispel **misconceptions** (Bennington et al, 2025)
- Improve **awareness** and knowledge (Vernon et al, 2021)

Our Aims:

Coproduce the **key components of an awareness campaign** focusing on speech and language therapy for people with primary progressive aphasia and their care partners

Understand the impact of a coproduced and delivered awareness campaign on knowledge and awareness of PPA and the role of the speech and language therapist

PPA Awareness Day
April 2nd 2027

“It was wonderful when there was a consensus from those living with PPA and their families that SLT had delivered ‘communication therapy’ and was so much more than their original ‘traditional’ expectations of SLT”

Methods:

Our project is inspired and designed with people with PPA using the People with Aphasia and Other Layperson Involvement – PAOLI Framework.

Results:

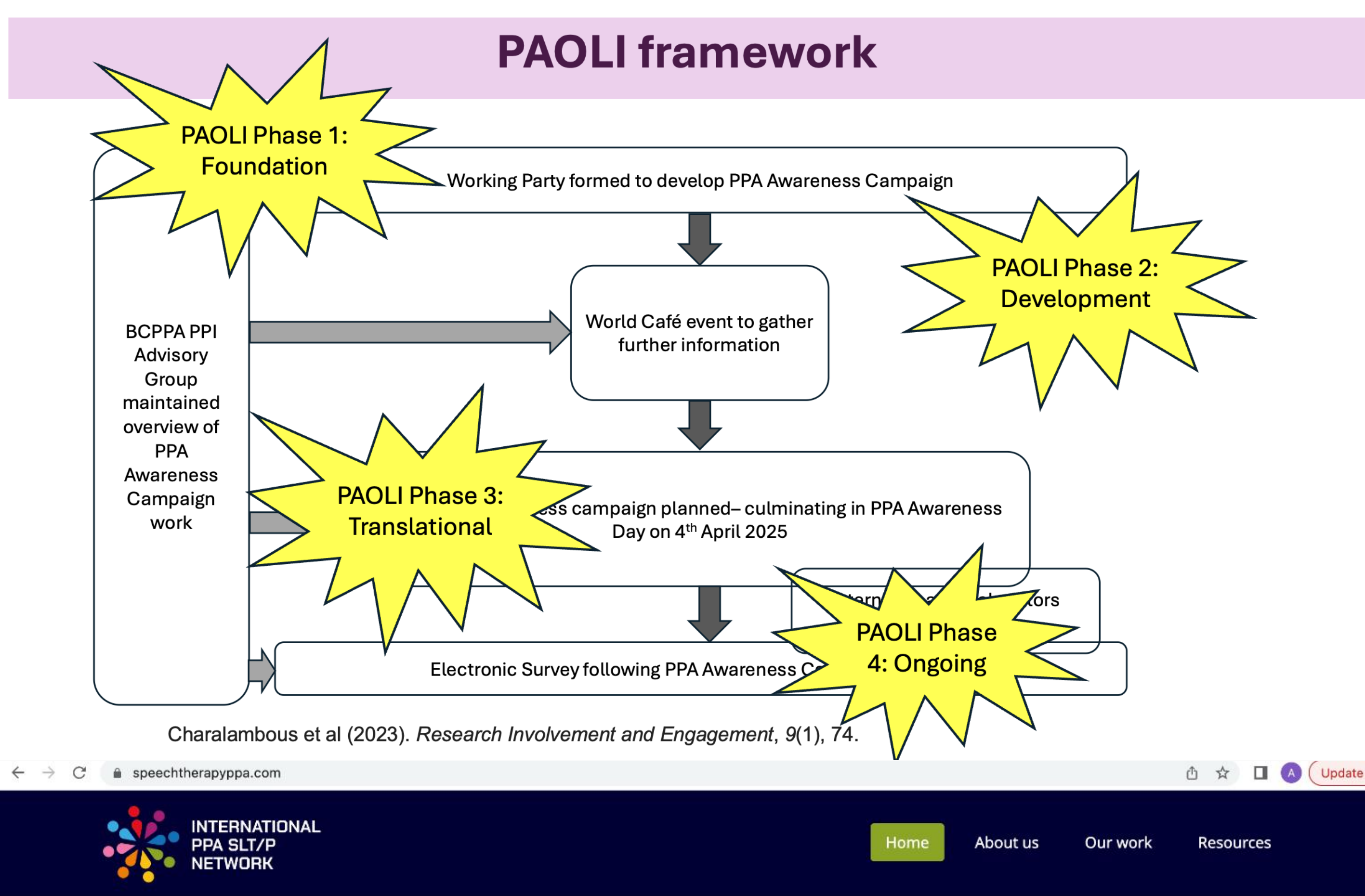
ACTIVITY	DATA (correct as of 25 th May 2025)
Launch	X post viewed more than 3,300 times.
Re-release of a Rare Dementia Support lived experience interview	X post viewed more than 2,500 times. 4,221 views since October 2020-May 2025
NIHR Dementia Research podcast	X post viewed more than 2,600 times. 209 views on YouTube
Brainy Speech podcast	X post viewed more than 343 times. Downloaded 30 times
Promotion of resources - Book launch	X post viewed more than 1,200 times.
Co-produced photo montage	X post viewed more than 1,600 times.
Person with PPA shared their poetry	X post viewed more than 563 times.
UCL Giving Voice podcast	X post viewed more than 1,000 times.
Lobbying at the Houses of Parliament to raise awareness.	10 parliamentarians attend the event. X post viewed more than 1,300 times.
PPA Awareness Day – webinars	Australia: 350 registered Canada: 250 registered France: 319 registered Greece: 391 registered Italy: 350 registered UK: 702 registered USA: 101 registered

Total of 2463 attendees worldwide

Discussion:

The awareness day provided a **sense of community**

People with PPA and their families **inspired and co-produced** an international awareness campaign with **a lasting legacy**



Primary
Progressive
Aphasia
Awareness
A language led dementia

PRIMARY PROGRESSIVE
APHASIA (PPA)
AWARENESS DAY

The first ever PPA awareness day was held on 4th April 2024. Events and news information was shared across the world. You can access the webinars from the UK, USA, Greece, Italy, Canada and France here:

UK Webinar

USA Webinar

Greece Webinar

Italy Webinar

Canada Webinar

France Webinar

