

Speech and language intervention in primary progressive aphasia: an ERN-RND survey



DG/WG
FTD

Introduction

Primary progressive aphasia (PPA) are rare neurodegenerative disorders with prominent speech and language impairment and often associated with pathologies within the frontotemporal lobar degeneration spectrum.

Diagnosis is often delayed, and therapeutic options are sparse.

Work Plan

Survey to evaluate current clinical practice with regards to available PPA management options.

Information on referral pathways, proportion subtypes, characteristics of language assessment and speech and language therapy (SLT)

All **ERN-RND FTD sites** (n= 34) were invited to complete the survey

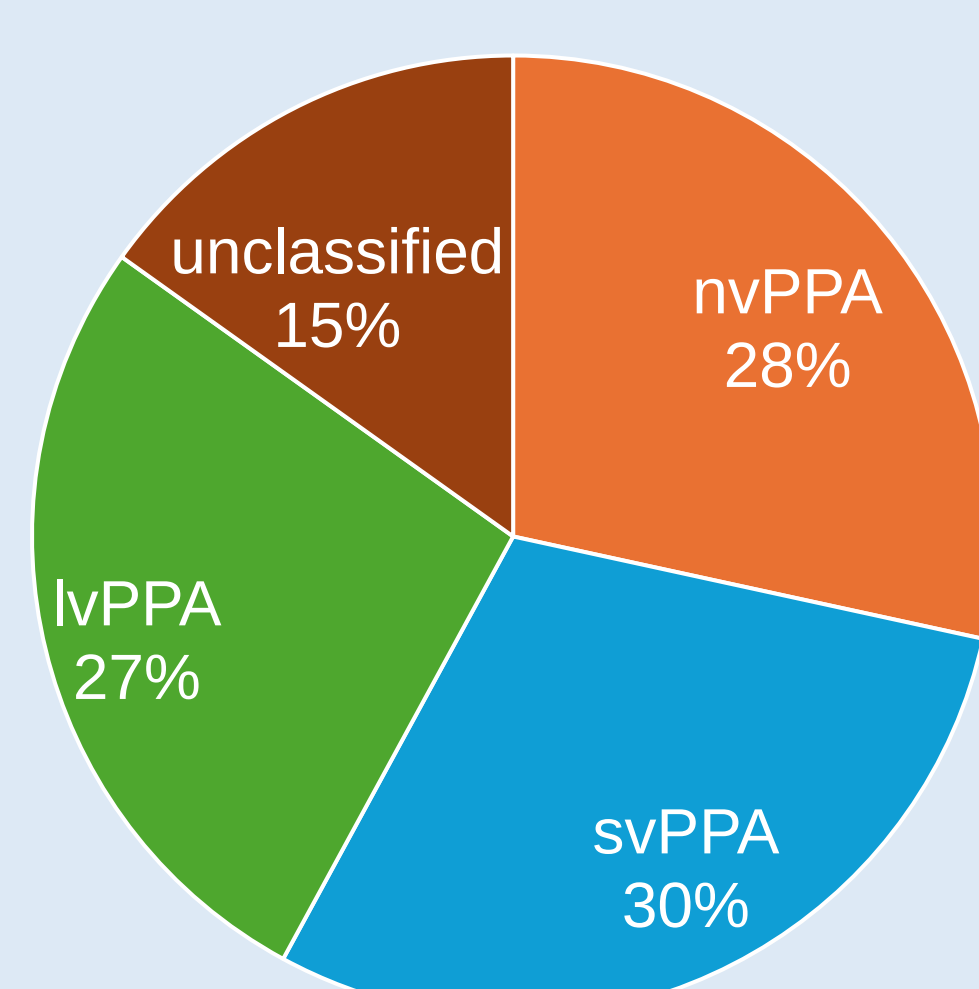
Results

Eighteen respondents of **18 centers** (53% of all ERN-RND FTD sites) from **11 countries** participated.

Referral patterns: mostly by neurologists and psychiatrists

Timespan to PPA diagnosis: first symptoms to first consultation was one year and to PPA diagnosis another year.

Average % of PPA subtypes



SLT Diagnostic and Treatment

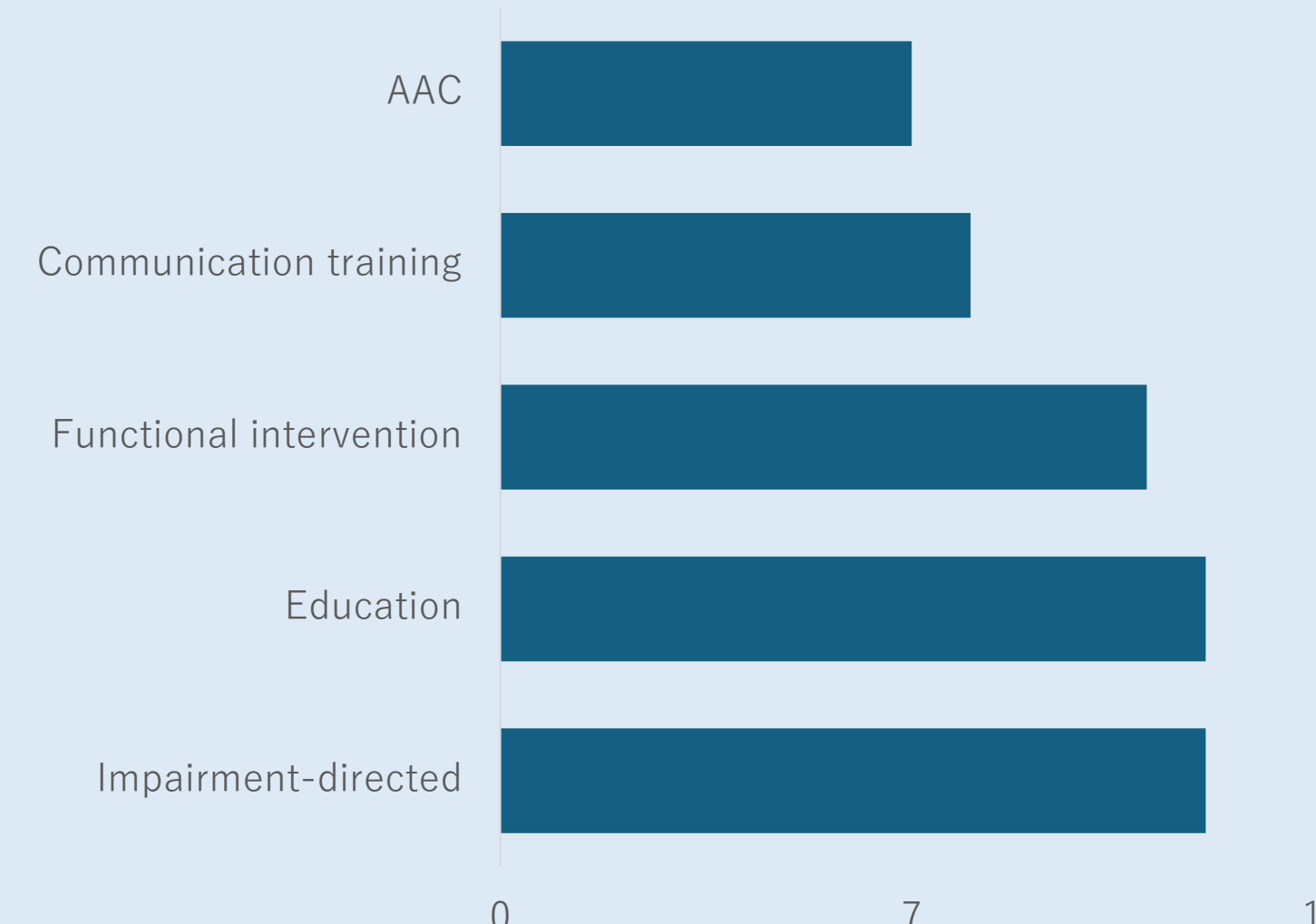
SLT Diagnostic

Available SOPs for PPA diagnosis/assessment: 71%

Language assessment

- Clinical language assessment 78.5%
- Standardized language tests 92%
- Patient related outcomes 42.8%

Type of SLT treatments



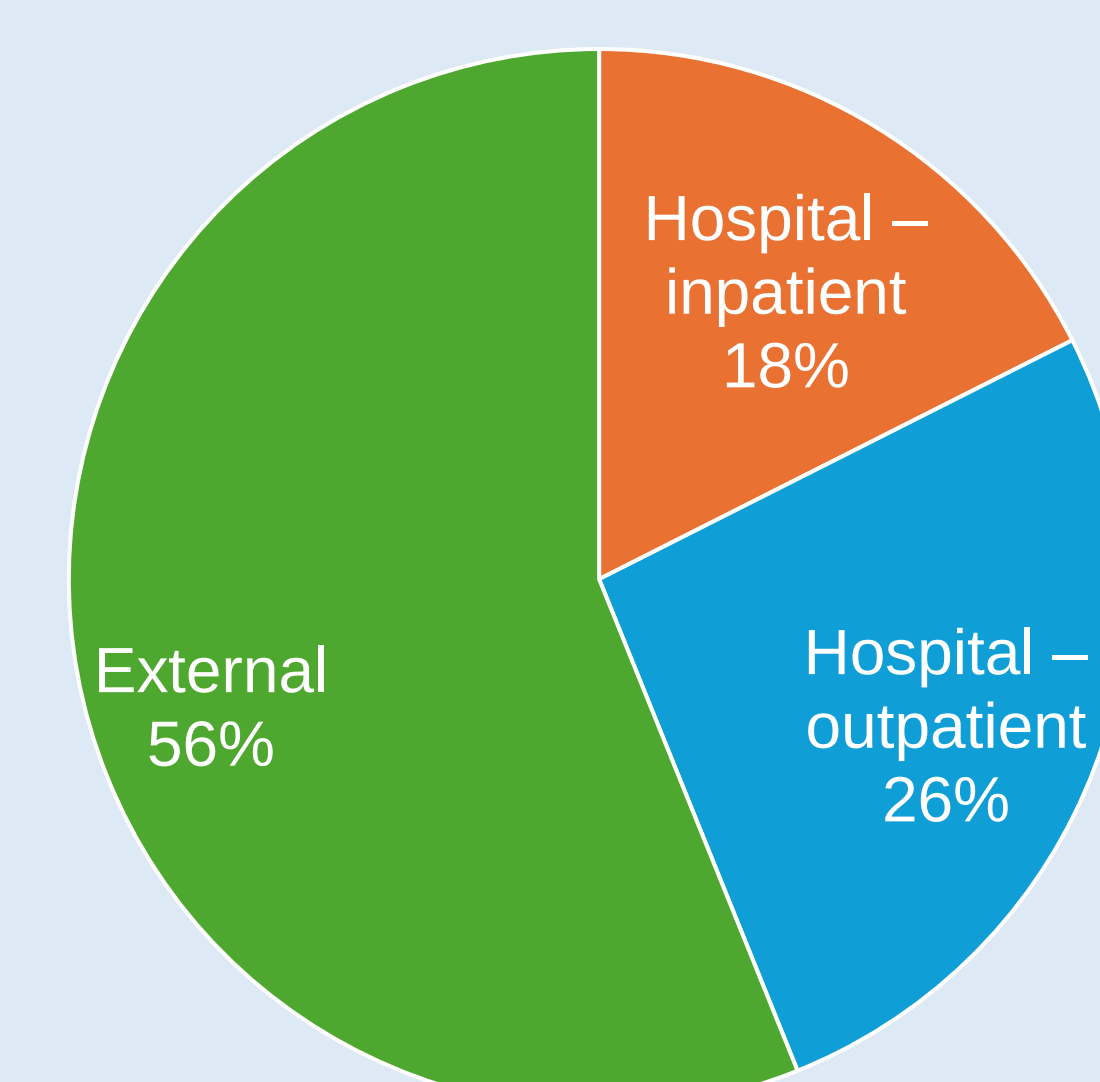
SLT Treatment

Treatment intensity 1.5x/week
Regular continuous therapy 57% over 5 months

Type of sessions

Individual sessions 78%
Telerehabilitation - only one centre 5%
Combined - only one centre 15%

Reimbursement – 78% (64% entirely)



Outlook

Key findings include:

- PPA subtype distribution varied across centers.
- 50% have in-team SLT, and 71% used standardized assessment procedures.
- Average SLT lasted 1.5 hours weekly, with 57% offering therapy over 5 months.
- Partial SLT reimbursement was available in 78% of centers, full reimbursement in 64%.
- Patient and family education occurred in 85% of centers.
- SLT was provided in-house for 44% of centers and outsourced for 56%.

These results can **guide SLT prioritization and treatment in PPA.**