

APPENDIX 1: Survey Questions

Section 1: Your clinical background

1. My job title is (open box)
2. How many years post-qualification are you? Please select one option.
 - Newly Qualified
 - 1-2
 - 3-4
 - 4-10
 - 10+
3. What is your current banding? Please select one option.
 - Newly Qualified Band 5
 - Band 5
 - Band 6
 - Band 7
 - Band 8
 - Other, please specify.
4. What healthcare service is your position funded by? Please tick one box:
 - Acute Health Care
 - Mental Health Care
 - Primary Care
 - Charity / Third sector
 - Independent / Private
 - Other, please specify
5. Which of these categories most closely represents where you work geographically?
 - Please tick one box:
 - South west
 - South East
 - London
 - East

West Midlands
East Midlands
Yorkshire and The Humber
North West
North East
Ireland
Wales
Scotland
Outside the UK

6. Have you EVER seen a patient with confirmed or queried PPA?

Yes/No

[If no please finish the survey now and enter submit]

7. Which setting have you seen patients with PPA in? Please tick all those that apply.

Acute Medical
Inpatient Rehabilitation Unit
Outpatients
Community- domiciliary, ESD
Memory Clinic
Other, please specify

Section 2: Number of patients, types of patients and where from?

8. Please estimate how many patients with PPA you have had on your caseload over the last 24 months? (please indicate a specific number)

9. Please estimate the age range of the patients referred:

< 50 years of age
50-60 years of age
60-70 years of age
>70 years of age

10. Please estimate what percentage came from the following backgrounds?

English speaking background only

Non-English speaking background

Bi / Multi-lingual background

If you saw individuals who spoke languages other than English, please list below the languages used:

11. Of the patients referred to you with PPA what were their current or previous professions:

(Please estimate what percentage were from the following professional areas)

Higher managerial, administrative & professional occupations

Intermediate occupations (such as supervisory, clerical & junior managerial, administrative, professional occupations)

Routine and manual occupations (such as skilled, semi-skilled & unskilled manual occupations)

Never worked or long-term unemployed

12. Do you feel there are people with PPA who haven't accessed the services you provide?

Yes/No

If yes what are some of the barriers (please tick all that apply):

Geographical location

Language barrier

Offered by decline

Service criteria

Other: (please explain)

13. Compared to previous years do you feel the number of patients with PPA on your caseload has (please tick one box):

Increased

Decreased

Stayed the same

If increased or decreased, please explain why you think this has happened:

14. Which professionals mainly refer people with PPA to the speech and language therapy service where you work? (tick all that apply)

Psychiatrists

Neurologists

Geriatricians

GPs

Psychologists

Other Speech and Language Therapists

Other:

15 What were the symptoms that prompted the referral to your service?

(Please estimate the percentage of referrals for each item)

Word finding difficulties

Slurred speech

Volume of speech

Swallowing difficulties

Other:

16. Prior to their referral to you, were the patients and their family members made aware of their diagnosis of PPA?

Always/mostly/sometimes/occasionally/never

17. If the patient/family members were NOT made aware of the diagnosis, what other terms / labels were used by the doctor to describe the condition, if any? (open box)

18. If the patient/family member have been made aware, which of these terms was used?

Primary progressive aphasia

Logopenic PPA

Semantic PPA

Non-fluent PPA

Semantic dementia

Frontotemporal dementia

Other:

19. Were they informed that this was a type of dementia?

Always/mostly/sometimes/occasionally/never

20. What difficulties if any do patients report in getting a diagnosis of PPA? (open box?)

21. When are the majority of these patients being referred to you? (please tick one box)

Within a year of symptom onset (around diagnosis)

2-3 years post onset (mid-way through the disease process when language symptoms are still the primary issue)

4+ years post onset (later stage of the disease when cognitive symptoms have emerged)

Unknown

22. Do you have an established care pathway for people with PPA?

Yes/no

Please describe:

Section 3: Time spent on management of this patient group

23. Does your service stipulate how long an individual's intervention can last when they have a diagnosis of PPA? For example intermediate care often has a six-week intervention limit

Yes - Please tick the approximate number of sessions (please tick one)

1-2 sessions

2-3 sessions

4-6 sessions

6+ sessions

Other, please specify

No – How many sessions on average would you estimate you spend with an individual from this patient group

Please tick the approximate number of sessions (please tick one)

1-2 sessions

2-3 sessions

4-6 sessions

6+ sessions

Other, please specify

24. Please estimate how many sessions you spend on the following when working with patients with PPA and / or their families

Direct assessment of language and communication

Assessment of dysphagia

Contributing to diagnosis of PPA

Impairment-directed language intervention

Functional interventions to support communication

Management of dysphagia

Education/information for patient

Education/information for family

Education/information for staff

Joint language / communication focused intervention with patient and family/friend/other

Mental Capacity assessment

Case/care review meetings

Joint sessions with other disciplines

Group therapy

25. If you are providing functional interventions to support communication, in what setting would these ideally occur in your opinion? (tick one)

Inpatient

Outpatient

Domiciliary

26. Ideally how much time would you like to spend with someone with PPA on functional interventions to support communication?

Enter number of sessions:

Section 4: Specific assessment and intervention approaches

27. When working with people with PPA how often do you use each of the following assessments/tools?

Always/ often/sometimes/occasionally/never

Comprehensive Aphasia Test (CAT) - Swinburn, Porter & Howard (2004)

Psycholinguistic Assessment of Language Processing in Aphasia (PALPA) – Kay, Lesser & Coltheart (1992)

Boston Naming Test

Cognitive Linguistic Quick Test (CLQT) - Helm-Estabrooks (2001)

Arizona Battery for Communication Disorders (ABCD) - Bayles & Tomoeda (1993)

Barnes Language Assessment – Designed by Psychiatry of Old Age SIG members.

Mini Mental State Examination (MMSE)

Informal impairment based communication test/screen

Informal interview with person / family on personal history / conversation style / personality etc

Informal assessment or observation of communication in functional activities

If you use any other assessment tools give name/authors (if appropriate), and a brief description of purpose

28. When working with people with PPA how often do you use the following intervention options?

Always/ often/sometimes/occasionally/never

Impairment-directed interventions including naming, semantic attributes, lexical retrieval, object use, phonological skills,

Impairment-directed interventions for speech production (apraxia of speech)

Work on reading and writing

Activity participation rehabilitation e.g. working on communication activities for a cooking task or TV watching Functional communication e.g. practising the use of multi-modal strategies such as gesture, drawing, writing

Communication training for families /carers

Communication training for staff

High tech communication aid provision and training- e.g. making an informed choice about app/device and training the client to use it, developing a communication book / word book or diary system etc

Introducing the person and their family to social and support networks

If you use any other interventions please describe

Section 5: Outcome measures and planning for the future

29. Do you use any of the following as an outcome measure for patients with PPA:

Goal setting

TOMS (ref)

Language assessments e.g. naming, picture description

Self-rating scales

Speech and language therapist rating scale

Video-recording of communication

Other. Please specify

30. Please provide one example of a goal that you have set with a patient with PPA.
Open question:

31. Do you explicitly address any of the following in planning for the future with patients with PPA? Tick all that apply:

Cognitive changes and deterioration in communication

Legal, financial, health and social care issues, including assessment of capacity.

Driving

Family care supports such as respite

Family financial supports such as benefits

Other. Please specify:

32. Do you refer patients and their families to any of the following charity or third sector organisations? Tick all that apply:

PPA support group

Alzheimer's Society

Dyscover

Stroke Association

Connect

Other – please specify