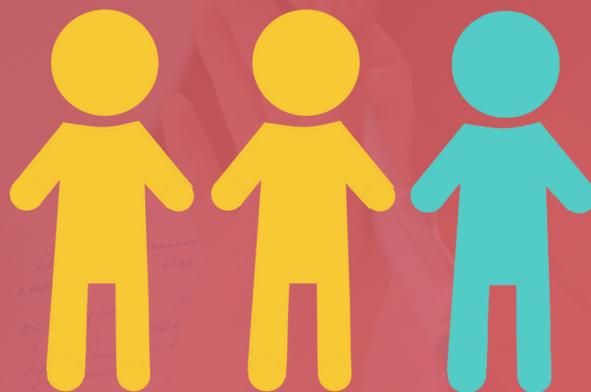


POLICY BRIEF

OPTIMISING STROKE CARE
FOR LIVING WELL WITH
APHASIA IN IRELAND



OPTIMISING STROKE CARE FOR LIVING WELL WITH APHASIA IN IRELAND

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EXECUTIVE SUMMARY

In this study, we looked at how to improve support for 'living well' with aphasia, an acquired language and communication impairment affecting one third of people with stroke.

We combined the views of people with post-stroke aphasia (PWA) with data on current service availability to generate recommendations.

To optimise stroke care for living well with aphasia, we must ensure that people living with aphasia (including family and friends, where relevant) have the following, when and where needed, over time:

- Access to health services.
- Access to information.
- Opportunities to participate and to contribute meaningfully to society.

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- Acquired Brain Injury Ireland
- Aphasia Ireland
- Croí
- Headway
- Health Services Executive Mid-West
- Speech & Language Therapy (SLT) service
- Irish Heart Foundation
- Limerick Stroke Club

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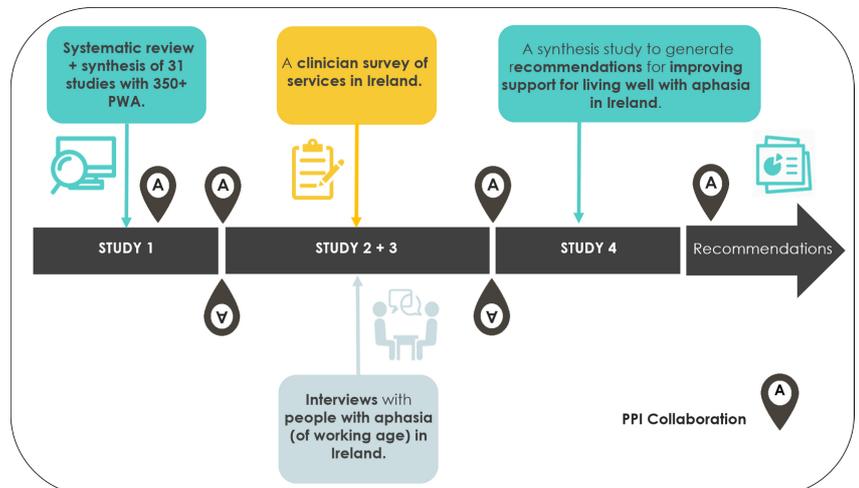
BACKGROUND

Aphasia is chronic with profound, diverse impacts on people's lives, relationships, and mental health. PWA have poorer outcomes on a range of measures (e.g., health-related quality of life, social networks, return to work, hospital length of stay and adverse events), but are underrepresented in stroke research. This has implications for the quality and appropriateness of stroke care and policy.

To deliver person-centred, integrated care, PWA must be included in stroke research and their experiences / perspectives must inform policy and practice. It is particularly important to harness the views of working-aged PWA who have unique psychosocial support needs.

WHAT WE DID

We worked with PPI collaborators at all stages of the research which comprised 4 studies (see figure).



KEY FINDINGS

- ✓ Working aged PWA, families and children experience significant life changes and upheaval in the long-term after a stroke.
- ✓ They require flexible support with parenting, accessing a diverse social network and finding opportunities for social connection, training, and employment.
- ✓ There are shortcomings and inequities in the provision of stroke care in Ireland including access to:
 - Stroke Units
 - Communication support in healthcare settings
 - Aphasia training for clinicians
 - Speech & Language Therapy
 - Peer networks, aphasia-friendly education, training, and vocational support
 - Stroke-specific, aphasia-friendly psychological care
 - Aphasia-friendly liaison and advocacy support
- ✓ Living well with aphasia is promoted by:

Equitable transparent access to a responsive, person-centred aphasia pathway + free at the point of care

Support with social participation in ways that respond to individuality + diversity.

CONCLUSIONS

To support living well with aphasia, we must ensure that PWA (+ family, friends) have, when + where needed, over time:

-  **Access to aphasia-friendly health services** (including SLT, psychological support, stroke / liaison and advocacy).
-  **Repeated access to a wide range of information** (e.g., about aphasia, health and community support services, self-management support, IT + social media).
-  **Opportunities to contribute to society in a personally meaningful way** (e.g., regular social contact / peer support, education/ training and paid employment)

ACTION REQUIRED

- 1 Meaningfully include people living with aphasia in setting the agenda for stroke research, policy and service development.
- 2 Ensure that all health workers involved in aphasia / stroke care have aphasia communication training.
- 3 Ensure that PWA are allocated a stroke liaison worker to improve long-term access to healthcare and to the community.
- 4 Develop, maintain and promote high-quality national information about living well with aphasia and access to support in Ireland.
- 5 Develop psychological support services for people living with aphasia.
- 6 Increase opportunities for PWA to access training, further education and paid employment.
- 7 Ensure that SLT services with an emphasis on improving life participation are available to PWA in the long-term, as needed.

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