

International stakeholder perspectives about Aphasia Awareness

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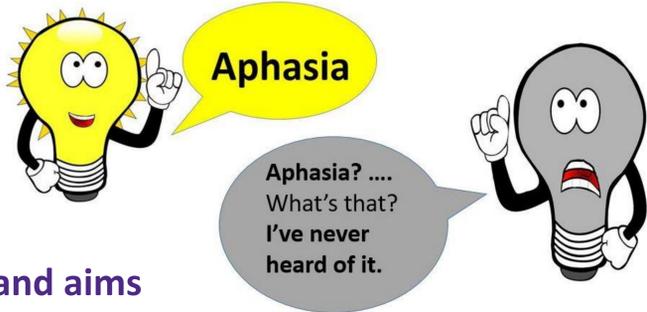
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Background and aims

The term “**aphasia awareness**” is often used but is difficult to define (Simmons-Mackie et al., 2020).

- What does aphasia awareness mean to different stakeholders?
- What do they want others to know about aphasia?
- What are they hoping to achieve by raising awareness of aphasia?

To date there has been no specific research exploring the perspectives of key stakeholders about aphasia awareness.

This study aims to explore **international stakeholder perspectives about aphasia awareness**.

Method

We ran **online international surveys with 2 stakeholder groups**:

- 1. People who work with people with aphasia** (Workers: Clinicians, Researchers, Assistants, Volunteers, Leaders of Aphasia Consumer Organisations, Leaders of Aphasia Centres)
- 2. People living with aphasia** (PLWA: People with aphasia, Family members, Friends, Carers)

Our **research advisors with lived experience** helped with the survey development, questions and response options and making sure the survey for people living with aphasia was **aphasia friendly**.

The data were analysed using **descriptive statistics** and **qualitative content analysis** of open responses.

Results and main contribution

Data from **n=306 workers** and **n=105 PLWA**, from **39 countries** spanning **6 continents** were included in the analysis.

Aphasia awareness was rated as **very or extremely important** by **95% of workers** and **93% of PLWA** around the world.

Nobody thought it was unimportant.

Top 5 reasons why aphasia awareness is important:

Workers	n (%)	People living with aphasia	n (%)
1. People with aphasia face barriers to communication and information every day	183 (60)	1. People with aphasia face barriers to communication and information every day	53 (51)
2. People don't know how to support communication for people with aphasia	182 (60)	2. Aphasia affects not only the person with aphasia but also their family and friends	49 (47)
3. Awareness is an initial step towards changing attitudes and behaviour towards people with aphasia	152 (50)	3. People are unaware that aphasia impacts almost every part of life	48 (46)
4. Aphasia affects not only the person with aphasia but also their family and friends	128 (42)	4. Aphasia can mask a person's intelligence	43 (41)
5. Awareness is needed for securing funding and services for people with aphasia	112 (37)	5. People don't know how to support communication for people with aphasia	41 (39)

What does “aphasia awareness” most mean to you?

Top 3 responses:

Workers	n (%)	People living with aphasia	n (%)
1. People know how to communicate with a person with aphasia	75 (25)	1. Educating people about aphasia	25 (24)
2. People understand the condition “aphasia”	64 (21)	2. People know how to communicate with a person with aphasia	19 (18)
3. Educating people about aphasia	58 (19)	3.a People understand the condition “aphasia”	14 (13)
		3.b People with aphasia are included in society	14 (13)

What do people need to know about aphasia to be “aphasia aware”? Top 3 responses:

Workers	n (%)	People living with aphasia	n (%)
1. What helps people with aphasia to communicate	260 (85)	1. Aphasia does not affect intelligence	79 (75)
2. Impact on people with aphasia	216 (71)	2. What helps people with aphasia to communicate	70 (67)
3. Aphasia does not affect intelligence	207 (68)	3. Impact on people with aphasia	69 (66)

What are the 3 most important things an aphasia awareness campaign should do?

Workers	n (%)	People living with aphasia	n (%)
1. Change the way people communicate with people with aphasia	177 (58)	1. Educate people about aphasia	61 (58)
2. Educate people about aphasia	168 (55)	2. Change the way people communicate with people with aphasia	52 (50)
3. Help people with aphasia to re-integrate into society	139 (45)	3. Increase the number of people who know that the condition exists	44 (42)

Conclusions

People who live and work with aphasia around the world view “aphasia awareness” as a **vehicle for reducing communication barriers in everyday life**.

They believe that to achieve this goal, **misconceptions and stereotypes about communication disability must be challenged**, and **practical education on how to communicate with a person with aphasia provided**.

Implication

The findings will be used to **co-design a unified, international, aphasia awareness campaign**.

References

Simmons-Mackie, N., Worrall, L., Shiggins, C., Isaksen, J., McMenamin, R., Rose, T., . . . Wallace, S. J. (2020). Beyond the statistics: a research agenda in aphasia awareness. *Aphasiology*, 34(4), 458-471. doi:10.1080/02687038.2019.1702847

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