Measuring what Matters: Interpreting meaningful outcomes in clinical care and economic evaluation for people with post-stroke aphasia

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Is the change on the outcome measure meaningful to the person with aphasia?

Should treatment stop, change, or continue?

Should resources be allocated to this treatment?

Retrospective, observational analysis of linked stroke data

AuSCR Australian Stroke Clinical Registry
AROC australasian rehabilitation outcomes centre
8,394 people with stroke

Acute hospital → Inpatient rehabilitation → 90-to-180-day outcomes

Results

Two thirds of patients with stroke had **communication support needs.**

There **isn't enough information about aphasia** in routinely collected stroke datasets.

Next steps: Support **development of stroke datasets** to collect information **relevant to people with aphasia.**

Sequential mixed-methods study

5 people with aphasia
8 speech pathologists

Focus groups → Consensus workshop

Results

Meaningful changes in aphasia recovery can be characterised as:
(1) different for every single person
(2) small continuous improvements
(3) measured by progress towards **personal goals** and
(4) **influenced by personal factors**.

In the **first six months** after stroke, meaningful changes can be **indicated by *slightly improved*** on the anchor rating scale.

Retrospective, observational analysis of randomised control trial data

COMPARE
216 people with aphasia

De-identified dataset → Person-level data → • EQ-5D-3 Level • SAQOL-39g

Results

EQ-5D-3L utility scores demonstrate **considerable accuracy** to detect people with aphasia who have poor quality of life.

Limitations of the EQ-5D-3L include **ceiling effects** and **weak correlations** with the SAQOL-39g: **use with caution!**

Further development of quality-of-life instruments is needed to ensure aphasia treatments are fairly prioritised.

Exploration of preliminary datasets from two observational aphasia studies

CHAT Comprehensive High-dose Aphasia Treatment
MEASuRES
16 people with aphasia

Anchor feasibility → Individual MIC values → Future directions

Results

The purpose-built anchor is **comprehensible** and **feasible for use by people with aphasia**.

Individual values of minimal importance **vary greatly**, highlighting the complexity of aphasia recovery.

In the future: A need to conduct **minimal important change** studies in a **larger, more diverse sample**.

Interested to read more?

Is communication key in stroke rehabilitation and recovery? National linked stroke data study.

'A meaningful difference, but not ultimately the difference I would want': A mixed-methods approach to explore and benchmark clinically meaningful changes in aphasia recovery.

A Comprehensive quality assessment for aphasia rehabilitation after stroke: protocol for a multicentre, mixed-methods study.

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