IMPROVING

RESEARCH OUTCOME MEASUREMENT IN APHASIA:
DEVELOPMENT OF A CORE OUTCOME SET

Sarah J. Wallace, Linda Worrall, Tanya Rose
The University of Queensland, Australia

Guylaine Le Dorze
Université de Montréal, Canada
WHY A CORE OUTCOME SET FOR RESEARCH?

1. We use too many different outcome measures

- 2012: 39 trials, 42 different outcome measures
- 2016: 57 trials, 44 different outcome measures

Systematic reviews of:
- tDCS\(^1\)
- Intensity of treatment and CILT\(^2\)
- Communication partner training\(^3\)
- Treatment for bilingual individuals\(^4\)
- Outpatient and community-based aphasia group interventions\(^5\)
- Semantic feature analysis\(^6\)
- Computer therapy for aphasia\(^7\)
WHY A CORE OUTCOME SET FOR RESEARCH?

2. Are we measuring what matters?

RQ-6: Identify and include outcomes the population of interest notices and cares about (e.g., survival, function, symptoms, health-related quality of life) and that inform an identified health decision.

(PCORI Methodology Standards)

RQ-6: Select outcomes based on input directly elicited from patient informants and people representative of the population of interest, either in previous studies or in the proposed research.

(PCORI Methodology Standards)
CORE OUTCOME SETS

- Agreed standardised set of outcomes and outcome measures\(^7\)
- Do not restrict the measurement of study specific outcomes
- Facilitate data combination, cross-study comparisons, deterrent to selective reporting\(^7-9\)
- Used in many health areas. See [http://www.comet-initiative.org/](http://www.comet-initiative.org/)
- Use encouraged by funding bodies e.g. NHS National Institute for Health Research & European Commission Horizon 2020
Our project:

What matters?

How can we measure it?

Can we agree on it?

Trilogy of stakeholder perspectives about important treatment outcomes

Systematic review of outcome measures

International consensus conference
Study 1

Which outcomes are most important to people with aphasia and their families? An international nominal group technique study framed within the ICF

WHAT WE DID

• Seven international locations

• Two participant groups:
  • (1) people with aphasia (n= 39)
  • (2) the family of people with aphasia (n = 29)

• Aphasia severity: mild to severe

• Time post-onset: 4 months to 17 years
THE NOMINAL GROUP TECHNIQUE

• What would you most like to change about your communication and the way aphasia affects your life?

• Outcomes prioritised by participants and assigned a number value

• Numbers tallied to give a prioritised list of outcomes

• Analysed using qualitative content analysis and ICF coding
WHAT WE LEARNED

Important outcomes for both people with aphasia and their families span the ICF
WHAT WE LEARNED

Communication
“To speak in longer words and sentences”

Life participation
“Get to work; including evaluation of being able to work.”

Physical & emotional well-being
“More dignity and respect.”

Recovery
“To be seen as the same person I was before.”

Attitudes, Awareness and Education
“People don’t know what aphasia is. Awareness about aphasia”

Health services
“Software and aides free NHS”
WHAT WE LEARNED

• Important outcomes for people with aphasia and their families span all components of the ICF.

→ The relevancy and translation of research may be increased by measuring and reporting research outcomes which are important to people living with aphasia.

→ A broad role for clinicians working in aphasia rehabilitation.

→ The categories of identified outcomes may be used clinically as a starting point in goal-setting discussions.
Study 2

Which outcomes are most important to aphasia clinicians and managers? An international e-Delphi consensus study.

WHAT WE DID

- Three-round, international web-based Delphi exercise
- Two participant groups: Clinicians (n=265) & managers (n=53) from 25 countries
- Advertisement through national and international speech pathology and aphasia networks & snowball sampling.
The question: “In your opinion, what are the most important outcomes (results) from aphasia treatment.”
**WHAT WE LEARNED - TOP 10**

1. Family/carers/significant others understand how to communicate with people with aphasia – 99% consensus

2. The PWA can communicate with relevant communication partners – 97% consensus

3. The PWA is able to communicate in daily life activities (96%)

4. The PWA is able to communicate their basic needs (95%)

5. The PWA experiences successful communication (95%)

6. Family/carers/significant others understand the nature and extent of the PWA's communication impairment (94%)

7. The PWA is able to participate in life (94%)

8. The PWA has a positive & supportive communication environment and environmental barriers are reduced (94%)

9. Strategies/ techniques used by the PWA generalise from therapy to real-life (94%)

10. The PWA has effective communication (93%)
What we learned

• Clinicians and managers identified a broad role for themselves in aphasia treatment

• Important outcomes identified for both people with aphasia and their significant others.

• Top 2 outcomes both related to communication between the PWA and their communication partner: the dyad
Core outcomes in aphasia treatment research: An e-Delphi consensus study of international aphasia researchers.

WHAT WE DID

• Three-round, international web-based Delphi exercise
• Carried out between March 2014 and February 2015
• Purposive sampling
• We asked, “What constructs do you believe should be measured as outcomes in all aphasia treatment research?"
WHAT WE DID

- 80 researchers commenced round 1, with 72 completing the entire survey. High response rates (≥85%) were achieved in subsequent rounds
- 564 codes, 49 sub-categories, 13 categories, 2 themes
WHAT WE LEARNED

Consensus was reached for 6 outcomes:

1. Language functioning in modalities relevant to study aims;
2. Impact of treatment from the perspective of the person with aphasia (PWA);
3. Communication-related quality of life;
4. Satisfaction with intervention from the perspective of the PWA;
5. Satisfaction with ability to communicate from the perspective of the PWA; and
6. Satisfaction with participation in activities from the perspective of the PWA.
WHAT WE LEARNED

• Language matters

• The patient perspective matters

→ While measures of language function are frequently included in aphasia treatment trials, PROs are infrequently measured.
SYNTHESIS OF STAKEHOLDER PERSPECTIVES

- ICF coding used to identify similarities across stakeholder groups.
- A COS for aphasia treatment research should include measures relating to:
  - language;
  - psychological wellbeing;
  - communication;
  - health services; and
  - quality of life
A Systematic Review of Studies Reporting the Measurement Properties of Standardised Outcome Instruments for People with Aphasia.

WHAT WE DID

• Scoping systematic review of all studies reporting the measurement properties of outcome instruments which have been validated with people with aphasia.

• Full text journal articles were identified through searches of PUBMED, EMBASE, and CINAHL databases and through hand searching of journals.

• Secondary searches were performed for outcome instruments identified in the initial search.

• PRISMA guidelines and COSMIN recommendations for systematic reviews of health measurement instruments.
WHAT WE LEARNED (OR CONFIRMED...)

• We have a lot of outcome measures.
• In total, 184 references for 79 outcome instruments were ultimately included in this review.
• When considered in reference to the ICF, the instruments identified in the current review predominately measured Body Functions (n=49; 62%).
Study 5

An international consensus meeting to develop a core outcome set for aphasia treatment research.

COS meeting participants (In preparation).
WHAT WE DID

• Participants in the researcher e-Delphi invited to participate in an international consensus meeting in London on Tuesday.
• We reduced the number of measures using pre-defined criteria
• We considered each remaining outcome measure in terms of its psychometric properties and feasibility (in alignment with published COS guidelines)
• Voted for inclusion in COS.
WHAT WE LEARNED...
**WHAT WE AGREED ON**

<table>
<thead>
<tr>
<th>Language</th>
<th>The Western Aphasia Battery (WAB-R) (AQ+LQ)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychological</td>
<td>General Health Questionnaire (GHQ) 12-item</td>
</tr>
<tr>
<td>Communication</td>
<td>The Scenario Test</td>
</tr>
<tr>
<td>Quality of Life</td>
<td>Stroke and Aphasia Quality of Life Scale (SAQOL-39)</td>
</tr>
<tr>
<td>Participation</td>
<td>Outcome measure to be discussed further</td>
</tr>
</tbody>
</table>
FUTURE DIRECTIONS

• Gaps in measures – treatment satisfaction/patient reported impact of treatment
• Need for a participation measure
• A report on the outcomes of the meeting
• Implementation of the Core Outcome Set
QUESTIONS?

For further information

Sarah Wallace

s.wallace3@uq.edu.au

@SarahJWallace
REFERENCES


REFERENCES


