Implementing a Core Outcome Set for Aphasia Treatment Research: Barriers, Facilitators and the Development of an Action Plan.

ROUNDTABLE DISCUSSION
SARAH J. WALLACE, LINDA WORRALL, GUYLAINÉ LE DORZE AND TANYA ROSE
sarah.wallace3@uq.edu.au
A Core Outcome Set is an agreed set of outcomes and outcomes measures for use in treatment trials of a particular condition. These sets represent the minimum that should be measured and reported in all clinical trials of a specific condition, and are also suitable for use in clinical audit or research other than randomised trials. The existence or use of a core outcome set does not imply that outcomes in a particular trial should be restricted to those in the relevant core outcome set. Rather, there is an expectation that the core outcomes will be collected and reported, making it easier for the results of trials to be compared, contrasted and combined as appropriate; while researchers continue to explore other outcomes as well (see http://www.comet-initiative.org/).
Stakeholder perspectives on important outcomes from aphasia treatment.

Phase 1:
- People with aphasia
- Family members of people with aphasia
- Clinicians/managers
- Aphasia Researchers

Outcomes reaching consensus for each stakeholder group are linked to the ICF and synthesised to produce recommendations for outcome constructs which should or could be incorporated in a COS.

Phase 2:
Systematic review of studies reporting the measurement properties of outcome measures validated for use with people with aphasia.

Phase 3:
International consensus meeting.
Independent initiative of international health professionals interested in outcome measures in rheumatology.

Identifying relevant health outcome domains and endorsing valid, responsive, feasible health outcome measures/scales.

Rheumatoid arthritis, osteoarthritis, psoriatic arthritis, fibromyalgia, and other rheumatic diseases.

Iterative consensus process involving relevant stakeholder groups.

Consensus conferences take place every two years.
Barriers - Awareness

- Most researchers who did not report on the full COS were unaware of it during the design stage of their trial.

- Non-pharmacological trials: Many of the primary investigators were not rheumatologists.

- Of the researchers contacted, 90% said they would consider measuring the COS in a new trial.

- Consideration of methods for increasing awareness.
Facilitators

- Endorsement?
- Trial registries?
- Funding body recommendations?