

Whanaungatanga

Pepeha

- Ko Tapuae-O-uenuku Te maunga
- Ko Waiamakariri te Awa
- No Otautahi ahau
- Ko James tōku whanau
- Ko Rotherham tōku whanau
- No Ireland/Scotland/ England ōku tīpuna
- Ko Gary taku papa
- Ko Lois taku whaea
- Ko Ross taku Tane
- Ko Grace, Briar tōku Tamariki
- Ko Annette toku ingoa





Life Participation

Measuring conversation success in dyads where one person has aphasia: the development of a Patient Reported Outcome Measure.

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- **Advisory Team:**
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- Dr Kirstine Shrubsole -UQ
- Professor Claire Croteau- University of Montreal
- Professor Katerina Hilari- City University, London



Conversation

Conversation is key to
human relationships,
interaction and
identity

“Backbone to
relationships” (Boxer
2002)



Impact of Aphasia on conversation

- initiating topics,
- asking questions
- expressing day to day information
- Following the topic and understanding others

Can become challenging for many people with aphasia (Rautakoski, 2014).



Negative consequences

- Frustration and helplessness (Laakso, 2014)
- Disengagement from conversational partners (Northcott & Hilari, 2011)
- Family members and friends often feel more responsible for the conversation
- Develop behaviours that do not encourage participation from the people with aphasia (Croteau, Le Dorze, & Baril, 2007).



Improving the conversation skills of the dyad

- **Speech-language Therapy** that targets conversation for the person with aphasia and their primary conversation partner has **shown to be effective** (King & Simmons-Mackie, 2017; Simmons-Mackie, Raymer, & Cherney, 2016).
- May reduce risk of isolation
- Can improve conversation in the home and community

Conversation measures



Some target **conversation directly** such as the Measure of skill in Supported Conversation (MSC), Measure of Participation in Conversation (MPC) (Kagan et al., 2004) and conversational analysis methods (CA),



Target **conversation indirectly** but consider participation or quality of life such as the Stroke and Aphasia Quality of Life measure (SAQoL-39) (Hilari, Wiggins, Roy, Byng, & Smith, 2003).



There is not currently a PROM that targets conversation for a dyad

Complexities with how to measure conversation?

Communication Partner Training (CPT) has been identified as complex due to:

- the wide range of outcome measures in use (Bryant et al. 2017; Simmons-Mackie et al. 2016)
- The misalignment of aims of treatment with how conversation is measured.
- Are we measuring what is important to stakeholders? (Wallace et al. 2017)



Outcome measurement instruments

- **Patient-reported outcome measure (PROM):** A measurement based on a report that comes from the patient about the status of a patient's health condition without amendment or interpretation of the patient's report by a clinician or anyone else.
- **Clinician-reported outcome measure (ClinROM):** A measurement based on a report from a trained healthcare professional after observing a patient's health condition. A ClinROM involves a clinical judgment or interpretation of the observable signs, behaviours, or other physical manifestations thought to be related to a disease or condition.
- **Observer-reported outcome measure (ObsROM):** A measurement based on observation by someone other than the patient or a health professional. This may be a parent, spouse, or another non-clinical caregiver who can observe and report on a specific aspect of the patient's health.
- **Performance-based outcome measure (PerBOM):** A measurement based on a task(s) performed by a patient according to instructions that are administered by a health care professional.

Perception of conversation success in dyads where one person has aphasia



Largely unexplored



Subjective measure



May be unique to each dyad and individual in the conversation

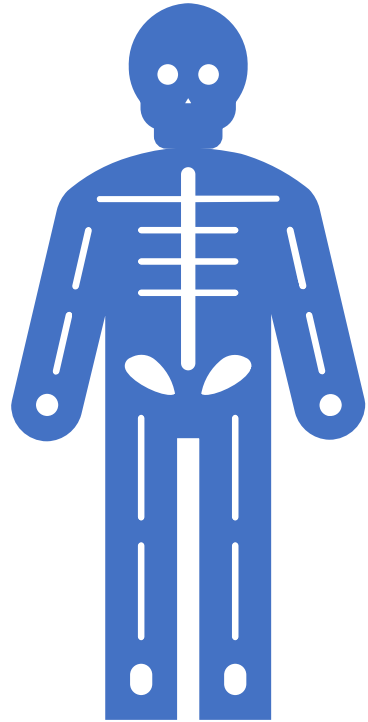


Best rated by the individuals participating in the conversation



Patient Reported Outcome Measures PROMs

- “Any report of the status of a patient’s health condition that comes directly from the patient without interpretation of the patient’s response by a clinician or anyone else” (US Food and Drug administration, 2009)
- Patients are the best source of information about themselves and the impact of health conditions (Amtmann et al., 2011)



Why use PROMs?

- (1) Patients can be **most accurate** in describing their own symptoms, pain, function and quality of life;
- (2) PROMs can be used in clinical settings to **support shared decision making and patient-centred care**;
- (3) PROMs can generate **valuable data** on treatment effectiveness, adverse events and variations in healthcare delivery and outcomes to inform efforts to **improve quality and safety**.

Williams et al. (2016)

Benefits of PROMS for Aphasia rehabilitation

1

Support best practice in goal setting and outcome measurement (Wallace, Worrall, Rose, Le Dorze, et al., 2017; Worrall et al., 2011).

2

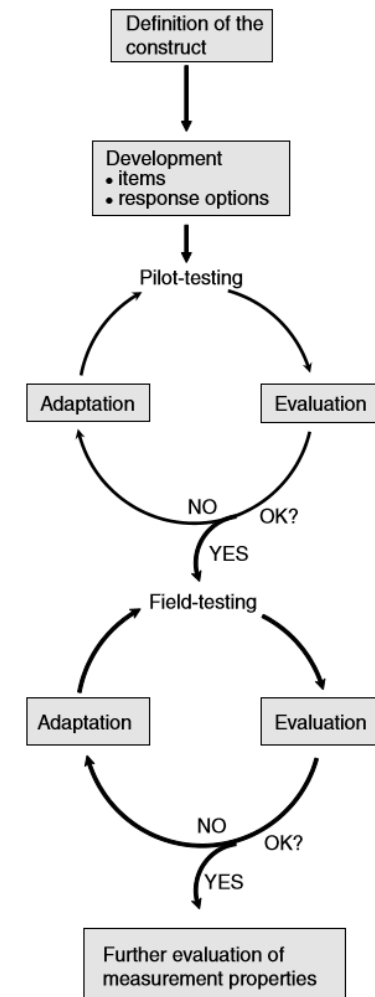
Assist to capture meaningful outcomes for PWA and PCP regarding communication from their perspective, (Eadie et al., 2006; Leaman & Edmonds, 2019)

3

Provide tools that are feasible for clinicians catering for a wide range of severities (Arnold et al., 2019)

Development of a new PROM- de Vet et al 2011

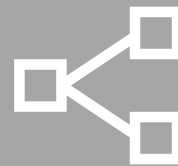
- 1) Define the Construct
- 2) Choice of measurement method
- 3) Selection and formulating the items
- 4) Scoring Issues
- 5) Pilot Testing
- 6) Field Testing



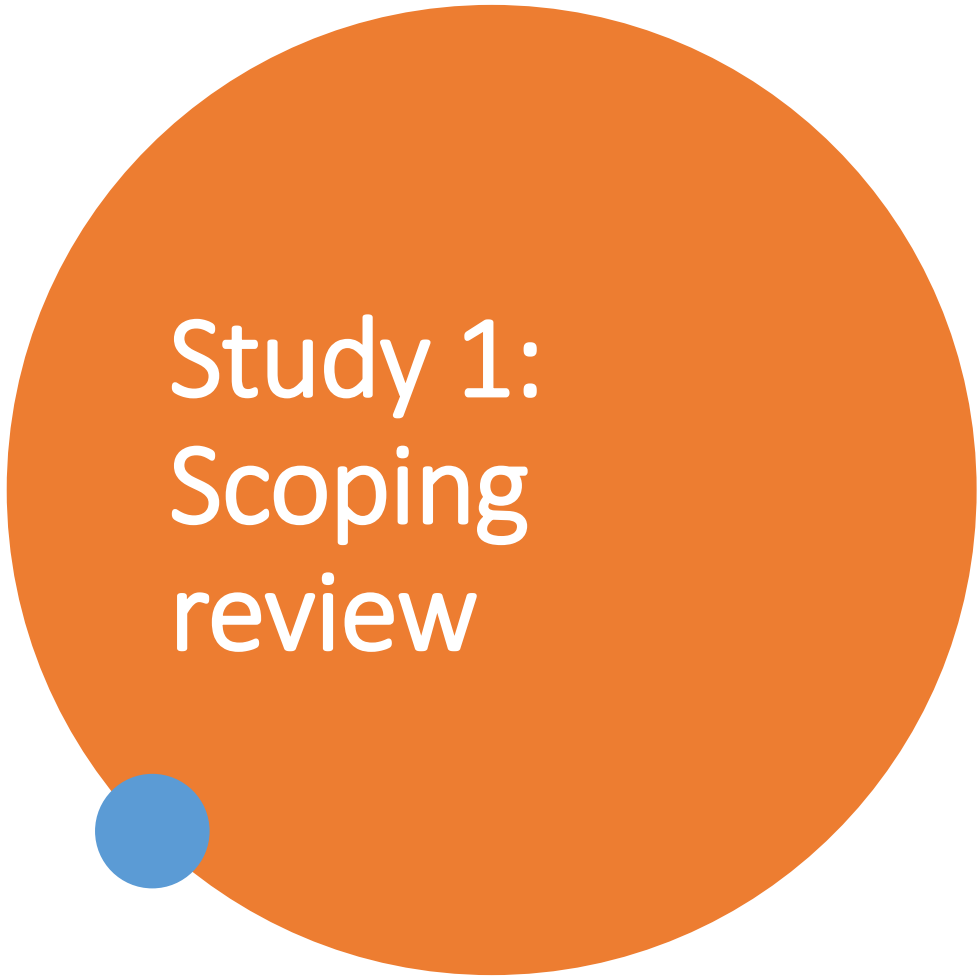
Aims of current research:



1) Explore the construct of successful conversation from literature and the perspective of people with aphasia and their primary conversation partners.



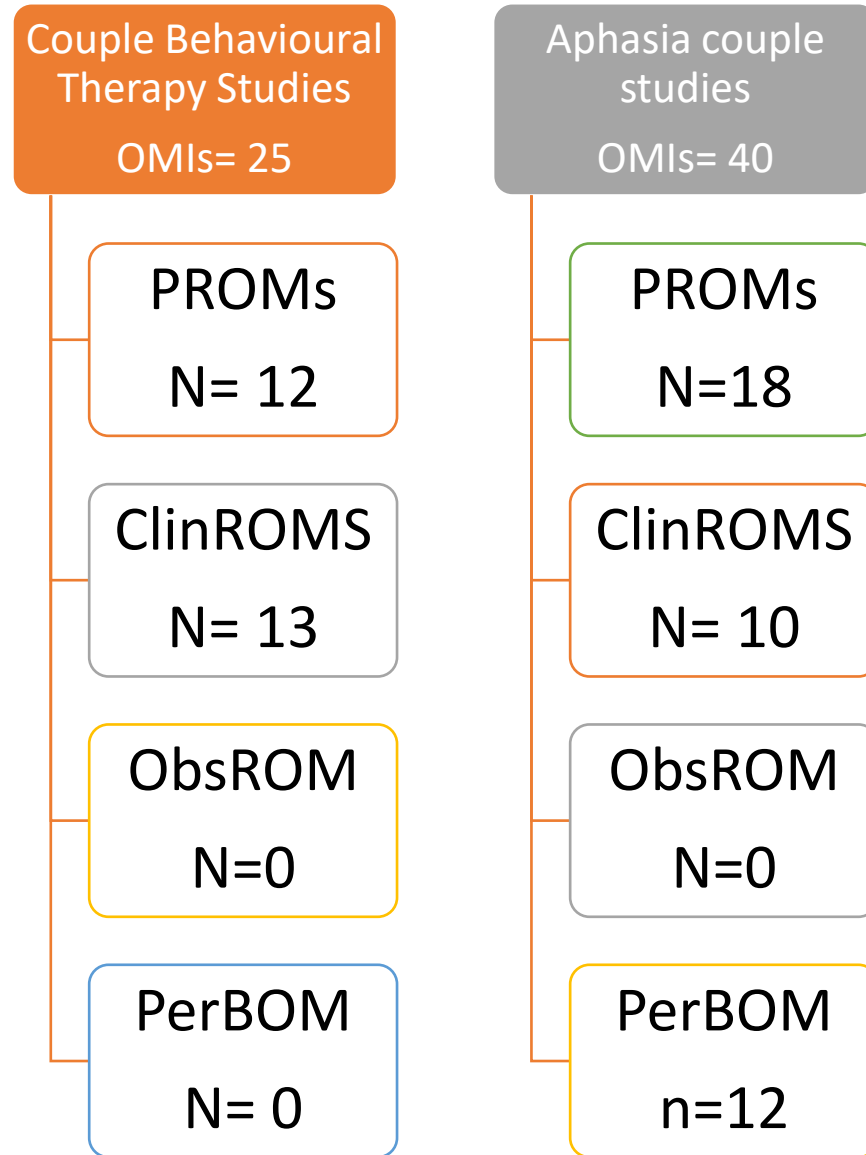
2) Develop a patient reported outcome measure (PROM) of conversation success for both partners in a dyad where one person has aphasia.



Study 1: Scoping review

- AIMS:
 1. To identify published treatment studies that aim to improve conversation or communication in either (a) couples where one person has aphasia or (b) couples who do not have aphasia or any other communication or neurological disability (neurotypical).
 2. To identify outcome measurement instruments for conversation or communication used within identified treatment studies
 3. To describe the content and format of identified PROMs that measure conversation or communication.

Results overview



Analysis of content of Aphasia PROMS- Refined ICF linking rules

PROMs Aphasia	Main Concept (What is measured)	Perspective of Responder	Category of response option
Understanding of Aphasia and Communication (study specific measure)(Blom-Johnson et al 2013)	Impact of intervention on conversation	Appraisal single	Likert- Intensity scale
Estimation of Conversational Skills (study specific measure))(Blom-Johnson et al 2013	Conversation skills	Appraisal Single	Likert- Intensity scale
Communication Outcome after Stroke scale (COAST) (Long et al. 2008) /Carer Communication Outcome after Stroke scale (Carer-COAST) (Long et al. 2009)-	Communication effectiveness	Description Capacity Description performance Dyadic	Likert- Intensity scale
Communication Readiness and Use Index (CRUI)(Lyon 1997)	Communication effectiveness	Appraisal Description capacity single	Qualitative attributes
Self-rating measures : Fox, S.; Armstrong, E.; Boles, L. 2009.	Conversation	Appraisal Description performance Description capacity Single	Likert- Intensity scale

Analysis of content of couple therapy PROMS- Refined ICF linking rules

PROMs Aphasia		Main Concept (What is measured)	Perspective of Responder	Category of response option
Communication Pattern Questionnaire Short Form (Christensen & Heavey, 1990) Unpublished	n=16 (short form) n=0 (not available)	Positive (engaging and active listening) and negative patterns (withdrawal, negative escalation) of communication behaviour.	Descriptive performance Dyadic	Likert Scale of frequency of communication behaviour occurring
Communication Skills Test (CST; Jenkins & Saiz, 1995), Unpublished	n=32 n=2	Positive and negative patterns of communication behaviour.	Descriptive performance <i>When our talks get out of hand, we agree to stop them and talk again later</i> Dyadic	Likert Scale of frequency of communication behaviour occurring
Communication subscale from the Partnership Questionnaire (PFB) (Hahlweg, 1996)	n=10 n=3	Communication quality	Descriptive performance <i>We talk to each other for at least half an hour every day</i> Dyadic	Likert Scale of frequency of communication behaviour occurring

Research Advisory Group- stakeholders

Consultation with stakeholders

- Couples with aphasia
- Kaumatua
- Expert SLTs in Conversation partner training
- Expert researcher in engaging stakeholders



Te Ara Tika Principles; (Came, 2013)

- *Te Ara Tika* guidelines are a kaupapa Māori ethical framework based upon the application of tikanga (traditional Māori practices) and Western ethical principles
- whakapapa (relationships),
- mana (justice and equity),
- tika (research design)
- manaakitanga (cultural and social responsibility).

Creating a culturally safe space

- Involvement of Cultural advisors- Kaumatua and a couple who are Māori within the advisory group
- Whanaungatanga- extra meetings and visits with participants to get to know each other and form a connection
- Use of Te Reo terms and whakatauki
- Offer of karakia, waiata
- Provision of information about what will happen the data, ownership of outcomes
- Asking what they expect too

The role of the Advisory Group

- The role of the Advisory Group is to **advise on the development of the research project** and to act as a 'critical friend'.
- **Responsibilities**
 - To help us ensure that the **views of people with aphasia** and their conversation partners are included in the development of the MCDA.
 - To help ensure that the **project is running to time**.
 - To **highlight any issues** concerning **ethics** and **governance** of the study.
 - To advise on the how to **share the findings** throughout the study.

Guidance provided so far

Explaining **the nominal group technique** to people with aphasia

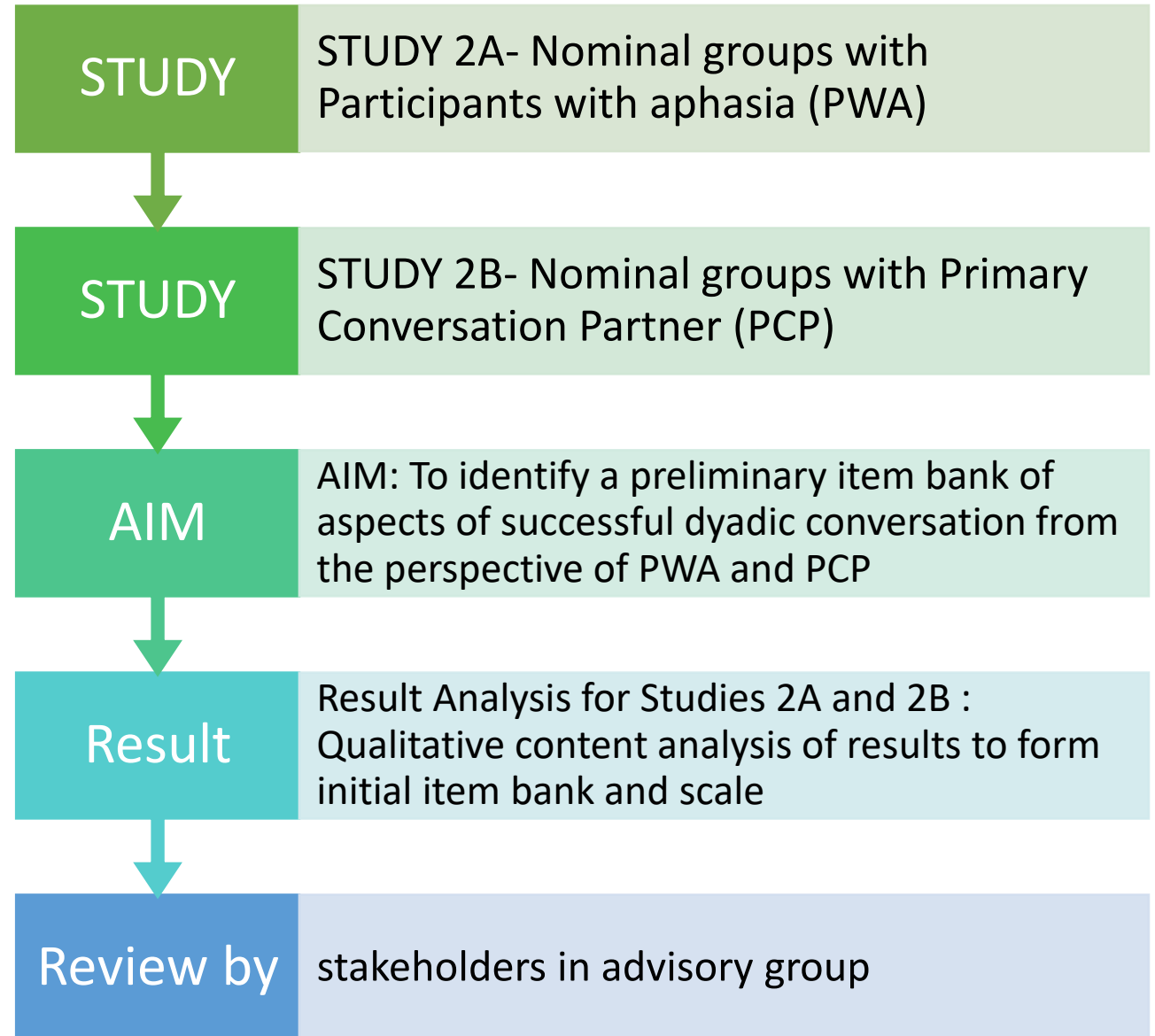
Discussing use of terms such as **dyad versus couple**

Discussing the term “**successful**” for the nominal question

Ideas about how to **run the member check meeting** and how to **present research findings** for people with aphasia

Step 2: Item generation

Study 2: Nominal Groups



What makes for successful conversation from the perspective of PWA and their primary conversation partners? Item generation using the Nominal Group Technique.

- Conversation therapy and CPT are used to treat conversation in aphasia
- Conversation therapies focus on behaviours of the dyad that help or hinder participation in conversation
- There are a lack of measures for providing quantifiable information about dyadic conversation
- How do we conceptualise successful conversation?
- We need a psychometrically robust outcome measure that gages the perspective of the dyad



Method

- People with aphasia and their primary conversation partners (n=20 dyads) shared their experiences of conversation success in a series of online focus groups (n=8) using the nominal group technique.
- Participants took turns to generate items conceptualising successfully conversation. Items were grouped into similar ideas and duplicates removed.
- Participants individually ranked their top three responses in order of personal importance.
- Content analysis was used to analyse participant responses across groups.
- Themed items were linked to the three-tier model of situated language (Doedens & Meteyard, 2020), with categories of: interaction, multimodal communication, and common ground.



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Step 3: Instrument development:



Combination of the items from Study 1, scoping review and Studies 2 A and 2B nominal groups to form the initial item bank



Formulation of first draft of Multi-item questionnaire

Preliminary Results for communication partners- top 3

PCP	1	2	3
PCP16	I let her drive the conversation more- helps her focus on what the topic is.	Be patient (not to get frustrated)	She needs to know she is being heard
PCP18	Patience	Self awareness	Love and laughter
PCP10	Time of day, avoid when fatigued	Relaxed environment	Be calm and easy going
PCP17	Reduce background noise	Patience (multi layered)	Love and laughter (be silly)
PCP19	patience	Avoid noise	humour
PCP13	Relaxed environment (keep it simple)	Talk about topics of interest	Spend time with grandchildren
PCP20	Self awareness	Knowledge of aphasia	Person is still the same

Preliminary results from participants with aphasia

PWA	1	2	3
PWA11	Conversation partner knows me	rest	Laugh and relax
PWA12	Conversation partner knows me	I go back to the topic if they don't understand	Conversation partner listens with patience
PWA7	CP asks questions to clarify	CP knows my aphasia	Familiarity with CP
PWA10	CP understands me	Laugh and relax	CP asks questions to clarify
PWA8	Conversation partner knows me	Less distractions	CP repeats the information to help me understand.

Study_3: Pilot testing of PROM- MDCA



Aim: Test face validity, content validity and reliability of the MDCA



Method: 1) Feedback from expert SLTS
2) Pilot test on 15-20 dyads



1) Questionnaire for expert SLTs with experience in aphasia rehabilitation



2) Cognitive interviews with participants, PWA and PCP

Messages from People with Aphasia





Questions?

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Thank you- Nga
mihi nui

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