From Caregiver Reflection to Patient Self-Insight

A Multidisciplinary Approach to Developing a Patient Self-Report Functional Communication Tool for Adults with Acquired Communication Disorders following Acquired Brain Injury

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01 Background

Communication is uniquely human — it shapes how people connect with family, sustain friendships, and take part in their communities. For adults with aphasia or dysarthria after acquired brain injury (ABI), recovery is not only about regaining language ability measured in standardised tests, but about **resuming meaningful communication in daily life**.

Standardised assessments do not fully capture the multidimensional reality of everyday communication — linguistic, non-verbal, social, emotional — nor the supportive context of caregivers, nor the patient's own awareness of their communicative experience.

02 What We Built First

ECP-C · CAREGIVER-REPORT FORM

We developed and validated the **Everyday Communication Performance scale – Caregiver-report form** (ECP-C; formerly FCR-CHECK) in 130 patient–caregiver dyads (94 aphasia, 36 dysarthria; Kim & Park, 2025; Kim & Choi, 2026).

.985	.998	130
Cronbach's α	Test–retest ICC	Dyads

Caregiver communication support emerged as a **structurally independent factor** that uniquely predicted patient functional communication beyond disability type and clinical characteristics ($\Delta R^2 = .166$, $\beta = .408$, $p < .001$).

Beyond measurement data, we observed that **completing the assessment itself prompted caregivers to reflect** on the patient's communication and on their own supportive interactions — suggesting reflective and educational value, not merely measurement value.

03 Aim & Three Questions

If a structured assessment can foster reflection in caregivers, **might a parallel patient self-report tool support similar reflection in patients themselves** — their awareness of their own communication, their engagement with therapy, and their sense of agency in recovery?

The abstract for this presentation posed three questions for the Delphi study. Since submission, the Delphi has been completed *and* the instrument piloted, allowing us to answer all three with data.

THREE QUESTIONS

Q1. Which functional communication domains are appropriate for patient self-report, given cognitive-linguistic and motor-speech constraints?

Q2. Which items require modification to support self-rating?

Q3. How can psychological dimensions — self-awareness, mood, adjustment after ABI — be appropriately integrated?

04 Multidisciplinary Delphi

A two-round Delphi study was completed with a **panel of 20 experts** drawn from four professions:

PROFESSION	CONTRIBUTION
Speech-language pathologists	functional relevance
Professors of speech-language therapy & special education	construct coverage
Rehabilitation medicine physicians	clinical feasibility
Clinical psychologists	**self-reportability**

This composition reflects our view that a patient self-report tool requires **both speech-language expertise** — so items address everyday functional communication — **and clinical psychological expertise** — so items can be safely self-reported by patients facing cognitive-linguistic or motor-speech challenges.

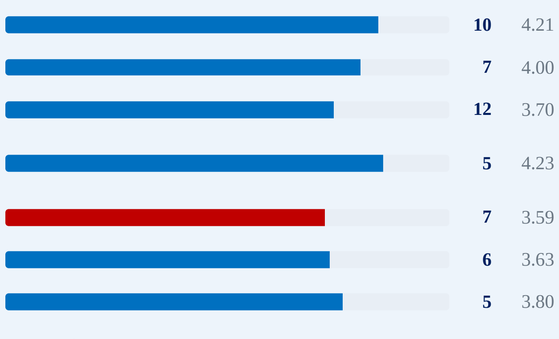
20	.84	32	89%
Panellists	Mean CVR (round 2)	Full consensus	Met CVR criterion

CVR criterion = .42 for 20 panellists (Lawshe, 1975).

05 Q1 · Which domains suit self-report?

The panel endorsed **seven domains**, retaining the four functional domains of ECP-C and adding three that only the patient can report: confidence, effort & willingness, and perceived environmental support.

ECP-S · 52 ITEMS ACROSS 7 DOMAINS



Bars = pilot domain means (1–5); figures at right = item count and mean.

Answer. All seven domains proved answerable. In the pilot (N = 27) there were **zero missing responses** across 52 items, and ease of understanding was rated **4.73 / 5** (95% rated ≥ 4). Adults with aphasia and dysarthria *can* complete a multidimensional self-report instrument.

5-point scale (1 = never, 5 = always); total 52–260. An overall self-rating of communication (NRS 0–10) is administered separately and excluded from the total score owing to its different metric.

06 Q2 · Which items needed modification?

Reverse-scored items collapsed. Round 1 endorsed all reverse-scored items. After panellists were informed that **patients showed response errors on reverse-scored items** during preliminary administration, round 2 ratings reversed sharply — a pattern not seen in any positively worded item.

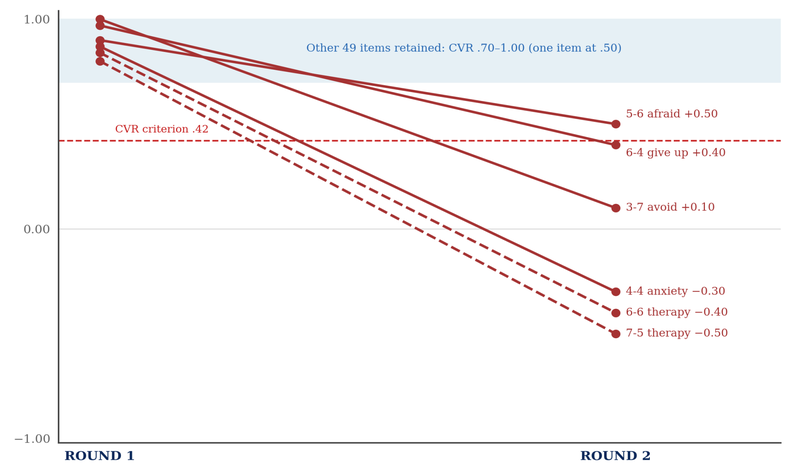


Figure 1. Solid = reverse-scored items (four). Dashed = speech-therapy-specific items, answerable only by patients currently receiving therapy. All six fell below or near the CVR criterion (.42) in round 2.

ITEM	ISSUE	CVR	ACTION
3-7	Avoids conversation rev	.10	Positive rewording
5-6	Afraid to speak rev	.50	Positive rewording
6-4	Wants to give up rev	.40	Positive rewording
4-4	Anxiety about failure rev	−.30	Removed
6-6	Therapy participation	−.40	Removed
7-5	Therapy helpfulness	−.50	Removed

Answer. Beyond wording, the pilot identified further refinement targets: **2 ceiling-effect items** (Q3, Q4 — both linguistic), **1 item** with corrected item–total $r < .30$ (Q9), and **12 item pairs** correlated $\rho \geq .80$. Patients themselves rated **length lowest** among acceptability items (3.64; 36% rated ≤ 3) while time burden was rated favourably (4.23) — converging evidence for item reduction.

07 Pilot Administration & Reliability

27	57.8	11/11/5	.967
Participants	Mean age (25–90)	Aphasia / Dys. / Both	Total α (.787–.937)

Aetiology: ischaemic stroke 14 · haemorrhagic stroke 4 · TBI 1 · Parkinson's disease 3 · ALS 3 · cerebellar ataxia 2. Severity: mild 15 · mild–moderate 4 · moderate 8. Time post-onset: M = 34.3 months (median 32, range 3–90) — chronic sample. Non-progressive 19 / progressive 8. Sex: 18 M / 9 F.

Only one domain separated the diagnostic groups: **non-/para-verbal communication**, rated lower by the dysarthria group (Mann–Whitney $p = .009$, $d = 0.71$) — consistent with the suprasegmental nature of motor speech disorders.

08 Q3 · How to integrate the psychological dimensions?

This was the question the abstract flagged as least settled. The pilot data answer it directly.

Psychological domains are not redundant with language ability. In the aphasia subgroup (n = 16), Spearman correlations with the K-WAB-R Aphasia Quotient show a clean split:

ECP-S DOMAIN	ρ with AQ	EVIDENCE
Linguistic communication	**.557***	convergent
Social communication	**.557***	convergent
Emotional communication	.127	discriminant
Communication confidence	.144	discriminant
Environment & support	**.022**	discriminant

* p < .05

> *Objective language ability tracked the linguistic domain — but was **unrelated to the psychological and environmental domains**. These are not a by-product of language impairment; they are a separate layer, and they require the patient's own voice to be measured at all.*

Answer. Integrate them as **distinct domains, not as adjuncts**. Domain intercorrelations ($\rho = .05$–$.82$) point the same way: the strongest pairing in the whole matrix is **confidence × perceived support ($\rho = .82$)**, while **linguistic × non-/para-verbal is $\rho = .05$** — a psychological–environmental axis running alongside, not within, the language axis.

09 An Unexpected Observation

Clinician-rated severity explained little of the self-report score: **$\rho = -.27$ (n.s.), $\rho^2 = .07$**. Within the moderate group alone, totals ranged from **91 to 242** of 260; within the mild group, from 126 to 256.

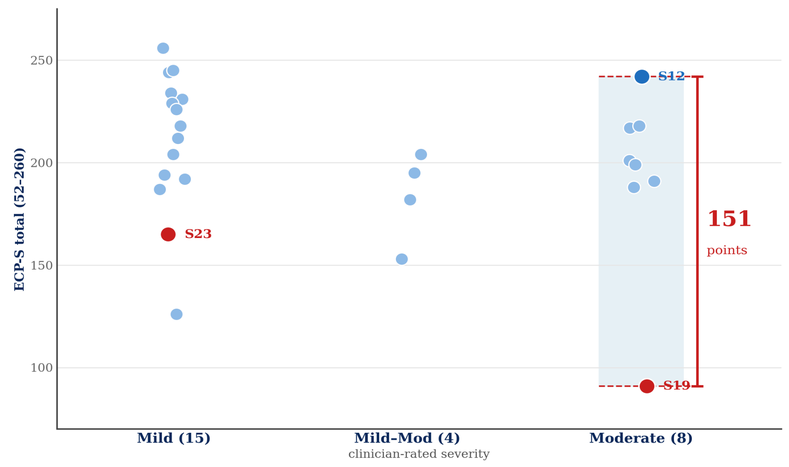


Figure 2. Participants with identical severity ratings differed by up to 151 points.

Post-administration interviews suggested why: respondents were **comparing against different internal baselines** — some with how they were at their worst, others with how they were before onset. Total score correlated strongly with use of scale endpoints ($r = .89$ with '5' responses; −.91 with '1–2').

> *One participant rated **mild** scored 165, with only **6%** of items rated '5' — the lowest in the sample — yet few '1–2' ratings. **Not "I cannot", but "I am not yet whole".***

By design, the ECP-S instruction does not tell respondents what to compare themselves against. Had one reference point been imposed, this variation would have been invisible.

10 Discussion

Interprofessional collaboration shaped the instrument. Clinical psychology expertise surfaced the reverse-scoring problem and legitimised the psychological domains; speech-language pathology anchored functional relevance. Neither profession alone would have produced this tool. This mirrors calls for psychologically informed practice in stroke rehabilitation (Kneebone, 2016).

Positive wording may be a prerequisite, not a preference. Reverse-scored items are widely recommended to reduce acquiescence bias (Weijters & Baumgartner, 2012), yet our panel converged against them once patient response errors were made explicit. Reverse items are known to impose additional cognitive demand and to introduce method variance even in unimpaired samples (Zhang & Savalei, 2016). In aphasia and dysarthria this burden appears prohibitive, and positive wording becomes a condition for valid self-report rather than a stylistic choice.

The psychological domains are not redundant. That the Aphasia Quotient tracked the linguistic domain ($\rho = .557$) but not confidence (.144) or perceived support (.022) indicates a layer of experience that impairment-level measures do not reach. The finding is consistent with evidence that communicative participation is predicted more strongly by self-efficacy and environmental factors than by speech severity (Baylor et al., 2013; Smith & Baylor, 2026), and with the ICF premise that participation is jointly determined by personal and environmental factors (WHO, 2001).

Self-report indexes perception, not performance. Clinician-rated severity explained 7% of variance in self-reported communication. Patients discharged as "within normal limits" may still experience substantial loss; low severity does not imply low burden. Total scores should therefore be interpreted alongside response patterns rather than as absolute ability estimates.

Limitations. This pilot (N = 27) is underpowered; non-significant findings reflect limited power rather than absence of difference. The sample was ambulatory and weighted towards mild severity, restricting range. Procedural details of administration were not systematically recorded. Reference points were inferred from post-administration interviews rather than measured.

Next steps. Exploratory factor analysis and full validation (target N = 150); caregiver–patient comparison within the same dyads; and a single reference-point item placed at the *end* of the form, so that this variation is recorded rather than inferred.

11 References

Baylor, C., Yorkston, K., Eadie, T., Kim, J., Chung, H., & Amtmann, D. (2013). The Communicative Participation Item Bank (CPIB): Item bank calibration and development of a disorder-generic short form. *Journal of Speech, Language, and Hearing Research*, *56*(4), 1190–1208.

Kim, H., & Choi, Y. (2026). Inter-rater reliability of the caregiver-report functional communication checklist (FCR-CHECK) for adults with aphasia. *Journal of Speech-Language & Hearing Disorders*, *35*(1), 35–47. [in Korean]

Kim, H., & Park, S. (2025). Development of a caregiver-reported functional communication checklist for adults with speech-language disorders. *Journal of Speech-Language & Hearing Disorders*, *34*(4), 1–16. [in Korean]

Kneebone, I. I. (2016). Stepped psychological care after stroke. *Disability and Rehabilitation*, *38*(18), 1836–1843.

Lawshe, C. H. (1975). A quantitative approach to content validity. *Personnel Psychology*, *28*(4), 563–575.

Smith, A. N., & Baylor, C. (2026). Communication self-efficacy for people with Parkinson's disease. *International Journal of Language & Communication Disorders*, *61*, e70217.

Weijters, B., & Baumgartner, H. (2012). Misresponse to reversed and negated items in surveys: A review. *Journal of Marketing Research*, *49*(5), 737–747.

World Health Organization. (2001). *International Classification of Functioning, Disability and Health: ICF*. WHO.

Zhang, X., & Savalei, V. (2016). Improving the factor structure of psychological scales: The expanded format as an alternative to the Likert scale format. *Educational and Psychological Measurement*, *76*(3), 357–386.

ECP-C was previously published as FCR-CHECK; the two names refer to the same instrument. · Ethics: PNUYH IRB (ECP-C 11-2026-040 · ECP-S 11-2026-081).

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