Invaluable benefits of 10 Years of the International Collaboration of Aphasia Trialists (CATs)

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The invaluable benefits of 10 years of the international Collaboration of Aphasia Trialists (CATs)

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Cover title:
Top 10 achievements of CATs

Key message (98 characters):
Overcoming decades-long research quality & career-building challenges through global collaboration

Twitter handle: @CATs_Aphasia
CATs Facebook: CATs.aphasia

Abstract

Aphasia research has traditionally been considered a (uni-disciplinary) niche topic in medical science. The international Collaboration of Aphasia Trialists (CATs) is a global collaboration of multidisciplinary aphasia researchers. Over the past 10 years, CATs has collectively taken a rigorous approach to systematically address persistent challenges to aphasia research quality. This paper summarises the achievements over the past decade. CATs' achievements include: Standardising terminology, advancing aphasia research design by aphasia expert consensus recommendations, developing a core dataset and intervention descriptors, facilitating the involvement of people with the language impairment aphasia in the research process, translating and adapting assessment tools into global languages, encouraging data sharing, developing innovative secondary data analysis methodologies and promoting the transparency and accessibility of high quality aphasia research reports. CATs' educational and scientific achievements over the past 10 years far exceed what individual researchers in the field could have ever achieved.

Non-standard Abbreviations and Acronyms

CATs = Collaboration of Aphasia Trialists
ESRs = early stage researchers
JSRs = junior stage researchers
TAP = Trials for Aphasia Panel

The notable benefits of international collaboration in the workplace are commonly known for businesses and industries, but less well documented for international research collaborations. Successful examples are emerging, including observations of a positive relationship between scientific impact of a publication and number of involved countries, but intra-national research collaboration remains the most prevalent form of collaborative science across disciplines [1]. In the stroke research domain, the most prominent international collaborative achievements include the research consensus statements of the International Stroke Recovery and Rehabilitation Alliance (ISRRA, previously known as SRRR) [2], the data sharing and harmonisation efforts of the Virtual International Stroke Trials Archive (VISTA) [3] and the Enhancing Neuroimaging Genetics through Meta-Analysis (ENIGMA) Stroke Recovery working group [4] — one of 26 disease working groups included in this worldwide consortium.

Aphasia research has traditionally been considered a niche topic in medical science, facing a variety of challenges, including:

(a) **uni-disciplinary** neurology, linguistics, psychology, speech and language therapy, or social science research perspectives on aphasia with limited knowledge exchange and career opportunities between disciplines, particularly for early/junior stage researchers (ESRs/JSRs);
(b) **disciplinary and geographical differences in research terminology, participant descriptors, outcome measurement selection, intervention reporting** and **research paradigms** that have restricted outcome comparisons, secondary data analysis and data meta-syntheses;
(c) **barriers faced by people with aphasia** in participating in the research process (particularly to inform research priorities and to co-design meaningful aphasia intervention and outcome measures), due to researchers' lack of knowledge or resources to appropriately create communication access for people with aphasia through ‘supported communication’ strategies, and
(d) **a lack of methodologically sound**, culturally appropriate clinical and research **assessment** and **intervention** tools for the multitude of languages impacted by aphasia globally, which in turn has hindered collaborative, international aphasia research and clinical implementation of milestone research findings.

Addressing these decades-long challenges to aphasia research quality has been the major mission of the Collaboration of Aphasia Trialists (CATs) over the past 10 years. CATs’ strategies involved identifying disciplinary differences and methodological gaps, harmonising terminology and intervention reporting, outcome measurement development, selection and cross-cultural adaptation based on relevant research guidelines [5], and developing sound evidence-based knowledge and innovative solutions to research barriers, including during the COVID-19 pandemic.

CATs brings together an international network of >300 multidisciplinary aphasia researchers from 41 countries and 43 languages and across all career stages (63 PhD students, 105 members within 8 years of PhD award, >140 senior researchers). The multidisciplinary membership includes professionals in neurology, neurorehabilitation, neuropsychology, (cognitive) neuroscience, speech and language therapy, linguistics, implementation research and related disciplines.

Originally established as European Cooperation in Science and Technology (COST) Action (funded by the European Union) focused on stroke-related aphasia (2013-2017), CATs has since expanded its scope to unite aphasia researchers globally and to include aphasias of non-stroke (neurodegenerative) aetiologies. This expansion was made possible by additional funding for administrative support from the non-profit Tavistock Trust for Aphasia (TTA; 2017-2026). As early

(pre-pandemic) adopters of virtual meetings, we recognised the greater accessibility of such meeting formats to the global research community and the minimal financial and scheduling barriers to participation, particularly in early career stages and for aphasia clinicians and researchers in low- to middle-income countries. Through digital formats and free membership, we promote equitable access to meetings, training and mentoring opportunities, and research resources, minimising financial, political, and geographical barriers to international collaboration. Over the past 10 years, CATs has additionally established active partnerships with the European Federation of the Neuropsychological Societies (EFNS; joint research activities), the International Association of Communication Sciences and Disorders (IALP; joint mentoring programme to support aphasia researchers and clinicians in low income countries), and the US-based international patient organisation Aphasia Recovery Connection (ARC; patient advisory groups to inform CATs-initiated aphasia research projects as well as international recruitment of research participants).

CATs' actionable plans (Figure 1) are to compile multidisciplinary, multilingual international aphasia rehabilitation research expertise through consensus research agendas, statements and recommendations (all non-competitive activities in mainstream funding rounds) in order to:

1) standardise **terminology** and harmonise **outcome assessments** internationally to facilitate design and outcome comparisons and to ease meta-synthesis of aphasia research data;
2) **enhance** the methodological **quality, replicability,** clinical **relevance** and **reporting** of aphasia research;
3) provide a freely-accessible **repository** of sound and multilingual research **tools** and (aphasia-friendly) **resources** to support researchers worldwide;
4) foster the future **research capacity and mentoring skills of ESRs/JSRs**, by providing training in current best practice **research methodology**, education in evidence-based **clinical care**, and offering international **mentoring, networking and leadership opportunities** (including visits to international centres of research excellence, where funding allows) for those seeking a research career in an aphasia-related discipline and thus qualifying as a future mentor for others [6];
5) strive towards linguistic, cultural, and geographic **diversity** in aphasia research and highlight the aphasia clinical and research needs of low- and middle-income countries, facilitated by CATs' Global Engagement Officers currently from South America, Africa, and Ireland; and
6) advance the **inclusion** of people with communication barriers in stroke research design, conduct, participation and dissemination.

CATs' educational and scientific gains achieved over the past 10 years in these actionable plans (summarised in Table 1) reflect the significant collective effort from:

- seven research working groups (listed in Appendix),
- three aphasia research dissemination teams for different stakeholder groups (Twitter/X, Facebook, e-newsletter),
- the Trials for Aphasia Panel (TAP) aiming to advance aphasia research methodology,
- four Officers (ESR/JSR, Global Engagement, Dissemination, Research).

Together with the CATs Chair and Deputy Chair, the 14 working group (Deputy) Leads and six Officers form the Executive Committee, which has been meeting quarterly over the past 10 years, bearing testament to members' commitment for enhancing aphasia research quality and the

careers of ESRs/JSRs in aphasia rehabilitation. Projects developed collaboratively, with participation of ESRs/JSRs, secured external funding of the equivalent of >10 million US$ to date and CATs collaborations have inspired ~50 peer-reviewed publications, including in general medicine/stroke journals (see references [7-55]). The latest testimony to the success of the collaboration is that CATs is the recipient of The Robin Tavistock Award 2023.

Table 1: The top 10 scientific and educational achievements of CATs from 2013 to 2023

1. **Global networking and mentorship**: Building links between aphasia researchers internationally	➢ Activities in 7 working groups ➢ Methodological advances (TAP, MAMA-Q) ➢ International consensus activities, such as developing a core outcome set for aphasia rehabilitation (ROMA COS) [7-14] ➢ Annual CATs virtual event weeks (2022 programme in Suppl. Material, Figure S1) ➢ Annual CATs in-person events alongside international aphasia conferences such as CAC, IARC, NAC, AcA (not during the COVID-19 pandemic)
2. **Research collaboration**: Developing joint international research collaborations on grants and publications	➢ Cross-national systematic reviews [15-18], observational [19] and clinical [20-22] trials ➢ Cross-national special journal issues, paper series [23,24] or projects [25-27] on aphasia-related topics ➢ Cross-national research funding (list in Suppl. Material)
3. **Knowledge:** Sharing the latest aphasia research	➢ Quarterly e-newsletter ➢ CATs Twitter ('@CATs_Aphasia'; aphasia news for researchers; > 2600 followers) ➢ CATs Facebook ('CATs.aphasia'; accessible aphasia research news for PWA, care partners, clinicians; ~ 500 followers) ➢ (CATs-commissioned) Video research abstracts on YouTube ('Aphasia Answers/X from CATs and ARC'; accessible, for PWA, carers, clinicians; 160 subscribers) ➢ Monthly webinar series with CATs Leads/Officers (for researchers, started in 2023), archived in CATs YouTube channel for researchers (@catsaphasia9864) ➢ CATs-organized symposia at international (stroke & aphasia) conferences (see Suppl. Material, Table S1 for the year 2023)
4. **Research quality**: Promoting aphasia research quality and integrity and reducing research waste	➢ Standardising terminology [28,29] and assessments [30-32] and intervention reporting [33,34] ➢ International consensus tutorials aiming to advance aphasia study designs [23,24,35,36] ➢ International consensus on aphasia research agenda [37] ➢ International consensus on cross-linguistic adaptations of outcome measurement instruments [32] ➢ Special task forces (such as: ROMA COS, MAMA-Q to improve the psychometric quality of aphasia diagnosis and

	outcome assessment or the MAP project to develop best practice guidelines to work with multilingual PWAs)
5. **Resources and Recruitment**: Providing freely available research resources on the CATs website and enabling global recruitment of research participants	➢ Online resources for planning & conducting & reporting randomised clinical trials (compiled by TAP) ➢ Online open access resource of 425 standardised aphasia measurement instruments across 48 languages ➢ Online application: The Aphasia Therapy Finder ➢ Free 'Aphasia-research during COVID-19' resources ➢ International participant recruitment by CATs email, Twitter, Facebook, personal communication by members ➢ Two 2021 aphasia surveys shared with CATs members (& Twitter followers), with >400 responses, 27 countries (manuscript in development)
6. **Career advancement**: Advancing careers of current and future aphasia researchers	➢ Regular 'Lightning talks' webinar series for ESRs/JSRs ➢ Mentorship programme for ESRs/JSRs ➢ Cross-national publications, involving ESRs/JSRs [15,24] ➢ Regular online tutorials by senior aphasia researchers, since May 2023 archived in CATs Youtube channel for researchers ➢ Online resources for ESRs/JSRs (registration required), including online forum
7. **New trials culture and data sharing**: Establishing a new culture of sufficiently powered randomised controlled trials and 'big data' meta-synthesis	➢ RCTs recently published in top-ranked general medicine/ stroke journals by senior CATs members [38-41] ➢ Initiating large-scale international aphasia studies [19] ➢ RELEASE database [42,43]: Archive of 5928 IPD across 170 aphasia RCTs and registry datasets from 28 countries; to date 6 peer-reviewed publications in general stroke/language pathology journals [19,35,44-47] ➢ Continuous expansion: CATs database
8. **Consumer Involvement**: Advancing the research involvement of people living with aphasia	➢ Free-to-access aphasia-accessible information sheets and consent form templates ➢ Development of 'Top 10 research priorities for people with aphasia, their families and healthcare professionals' [48] ➢ Publication series on best practice of PPI in aphasia research (4 peer-reviewed publications) [49-52] ➢ Free manual and templates to produce aphasia-accessible research summary videos ➢ Qualitative research to identify preferences of PWA for aphasia research video abstracts, in cooperation with our partner patient organisation ARC [53]

9. **Impact**: Impacting on clinical practice and policy	➢ International consensus on core outcome set for aphasia research [8,9] endorsed for clinical practice in several countries ➢ Treatment priority work [37,48] and systematic reviews on therapy efficacy [15,54] by CATs members directly impacting on national aphasia rehabilitation guidelines ➢ Free access to general stroke and aphasia-specific clinical guidelines on CATs website ➢ Establishment of a Clinical Advisory Committee in 2023 to identify facilitators and barriers of the clinical implementation of aphasia research results
10. **Inclusion**: Promoting diversity and inclusion of countries and languages underrepresented in aphasia research	➢ Global engagement team involves officers from 3 continents (Africa, South America, Europe) ➢ 5 language adaptations (Austria, Egypt, Greece, India, Serbia) of the Danish communication partner training program KomTil including training of local providers [55]

ARC = Aphasia Recovery Connection; COS = Core Outcome Set; ESR = early stage researcher; IPD = Individual Participant Data; JSR = junior stage researcher; MAMA-Q = Multilingual Aphasia MeAsures and Quality; MAP = Multilingual Aphasia Praxis; PPI = Patient-Public Involvement; PWA = people with aphasia; RCT = Randomised Controlled Trial; RELEASE = REhabilitation and recovery of peopLE with Aphasia after StrokE; ROMA = Research Outcome Measurement in Aphasia; TAP = Trials for Aphasia Panel; TiDIER = template for intervention description and replication;
(all weblinks last accessed on January 30, 2024)

In summary, CATs works to educate the next generation of aphasia researchers and mentors, connect international aphasia researchers of all career levels, reduce research waste across the research cycle, maximise the methodological rigor and clinical relevance of aphasia research outputs and fast-track research findings to benefit the lives of people with aphasia, their families and the healthcare professionals working with them.

CATs activities have achieved major new insights about aphasia rehabilitation during the past 10 years. Outstanding insights include (a) championing the use of patient public involvement and accessible materials in aphasia research, (b) the requirement of a consumer-informed international "core outcome set" [8,9,11] for aphasia research and routine clinical care and (b) based on the findings of our recent individual participant data network meta-analyses [42-47] that the best treatment outcomes are observed for intensive, functionally tailored, mixed receptive-expressive aphasia therapy with prescribed home-practice.

The benefits have far outweighed the hindrances, but collaborating across continents has also posed notable challenges, such as insufficient funding for in-person meetings (particularly for ESR/JSR members), administrative and IT support (e.g., for the CATs website, development of research data repositories), for kicking off novel research activities and few opportunities for funding of cross-continental research grants. Working across multiple time zones has been an additional challenge. The more globally inclusive the network, the more challenging it was to find suitable meeting times with various methods adopted to support participation including people participating very early/late in their own time zone, dual offerings of training seminars to support participation from different global regions, or sharing network roles with others in a different time zone to ensure representation during discussions despite the time chosen. Nevertheless, we hope that researchers and clinicians in other (niche) fields of stroke will follow CATs' path of fostering international collaboration to accomplish much more than the sum of individual researchers in a field could ever achieve, and in this way contribute to advancing their field in (what truly feels like) a quantum leap after 10 years. Any aphasia researcher or clinician, from any disciplinary background, at any stage of their career, may join CATs at https://www.aphasiatrials.org/join-cats/ – membership is free.

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List of the supplemental materials:

Supplemental Material

Table S1

Figure S1

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399 **Figure legend**

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401 Figure 1: CATs' membership and actionable plans

Appendix: Members of the CATs Executive Committee (as of December 2023)

Chair: Marian C. Brady,
Nursing, Midwifery and Allied Health Professionals Research Unit, Glasgow Caledonian University, Glasgow, United Kingdom and School of Health and Rehabilitation Sciences, University of Queensland, Brisbane, Australia

Deputy Chair: Caterina Breitenstein,
Department of Neurology with Institute of Translational Neurology, Germany

Trials for Aphasia Panel (TAP) Lead: Katerina Hilari,
Centre for Language and Communication Science Research, School of Health Sciences, City, University of London, United Kingdom

Research Officer: Sarah J. Wallace,
School of Health and Rehabilitation Sciences, The University of Queensland, Australia and Queensland Aphasia Research Centre, Brisbane, Australia

Early Stage Researchers Officers
Ruth McMenanim,
Discipline of Speech and Language Therapy, NUI Galway, Ireland

Hanne Gram Simonsen,
Center for Multilingualism in Society across the Lifespan, University of Oslo, Norway

Global Engagement Officers
Caroline Jagoe,
Department of Clinical Speech & Language Studies, Trinity College Dublin

Abena Asiedua Owusu Antwi,
Speech and Language Therapy Clinic, Korle-Bu Teaching Hospital, Ghana

Dissemination Officer: Natalie Gilmore,
Lab for NeuroImaging for Coma and Consciousness, Massachusetts General Hospital, Cambridge, USA

Working group 'Aphasia datasets'
Lead: Myzoon Ali,
Nursing, Midwifery and Allied Health Professionals Research Unit, Glasgow Caledonian University, Glasgow, United Kingdom

Deputy Lead: Erin Godecke,
Department of Speech Pathology, Edith Cowan University & Sir Charles Gairdner Hospital, Australia and Centre of Research Excellence in Aphasia Recovery and Rehabilitation, La Trobe University, Australia

Working group 'Aphasia assessments and outcomes'
Lead: Seçkin Arslan,
Laboratoire Bases, Corpus, Langage (BCL), CNRS, Université Côte d'Azur, France

Deputy Lead: Claudia Penaloza,
Department of Cognition, Development and Educational Psychology, University of Barcelona, Spain

Working group 'Prognosis and markers of aphasia recovery'
Lead: Cathy Price,
Wellcome Centre for Human Neuroimaging, Institute of Neurology, University College London, United Kingdom

Deputy Lead: Sasa Filipovic,
Institute for Medical Research, University of Belgrade, Serbia

Working group 'Effectiveness of aphasia interventions'
Lead: Miranda L. Rose,
School of Allied Health, Human Services and Sport, La Trobe University, Australia and Centre of Research Excellence in Aphasia Recovery and Rehabilitation, La Trobe University, Australia

Deputy Lead: Lucy Dipper,
Division of Language and Communication Science, City, University of London, United Kingdom

Working group 'Societal impact & reintegration of people with aphasia'
Lead: Suzanne Beeke,
Language & Cognition Research Department, University College London, United Kingdom

Deputy Lead: Lisa Anemaat
School of Health and Rehabilitation Sciences, The University of Queensland, Australia and Queensland Aphasia Research Centre, Brisbane, Australia

Working group 'Aphasia and cognition'
Lead: David Copland,
Queensland Aphasia Research Centre, School of Health and Rehabilitation Sciences, The University of Queensland, Australia and UQ Centre for Clinical Research, Faculty of Medicine, University of Queensland, Australia and Centre of Research Excellence in Aphasia Recovery and Rehabilitation, La Trobe University, Australia

Deputy Lead: Carolina Mendez-Orellana,
School of Speech and Language Pathology, Health Sciences Department, Faculty of Medicine, Pontificia Universidad Católica de Chile, Chile

Working group 'Implementation science in aphasia'
Lead: Natalie Douglas
Department of Communication Sciences and Disorders, Central Michigan University, MI, USA

Deputy Lead: Kirstine Shrubsole,
Queensland Aphasia Research Centre, School of Health and Rehabilitation Sciences, The University of Queensland, Australia and Centre of Research Excellence in Aphasia Recovery and Rehabilitation, La Trobe University, Australia