

### Collaboration of Aphasia Trialists Final Report 2013-2017

"Thanks to the 179 multidisciplinary, multinational and multilingual aphasia trialists the CATs network has achieved significant advances in the development and coordination of aphasia science, especially from the professional's point of view."

COST Action Rapporteur 2017



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### **Executive Summary**

The Collaboration of Aphasia Trialists (Cooperation in Science and Technology Action IS1208) supported the development of an international network of more than 170 researchers that bridged different disciplinary, linguistic, geographic and research paradigm perspectives to discover a shared ambition to enhance the rehabilitation and recovery of people with aphasia after stroke. While our COST Action network extended to include 26 countries several of our projects extended that network further, collaborating with researchers from another 10 countries (including USA, Brazil, Canada, Chile, Iran, South Korea and China).

We coordinated our research activities across 39 collaborative proposals (12 still under review or unfunded) reflecting our four research orientated Working Groups on (i) assessments and outcomes, (ii) predictors and prognosis, (iii) effective interventions and (iv) societal impact and reintegration. Researchers secured a further €1.1M in competitive external research grant awards to support their collaborative research activities. Seventeen projects were funded by the host academic institution. We also demonstrated the synergistic development of multiple parallel projects adapting an aphasia assessment tool into 14 languages, developing consensus on an ICF based definition of aphasia, created an international database of secondary individual participant data from aphasia researchers, evaluated the quality of aphasia intervention reports in the literature, reviewed the evidence of the effectiveness of interventions, evaluated the effectiveness of novel interventions in trial designs and explored ways in which we can support reintegration back into society of people with aphasia after stroke.

Our Action members have been published 16 papers to date. Additional manuscripts are in preparation. We delivered 7 workshop events and contributed to one consensus meeting. We presented our activities in 34 conference papers and additional posters. The Action functions and members' needs were well supported by our website. We hosted two international conferences and 3 training schools. We established the top ten aphasia research priorities and are developing an aphasia research agenda which will support a strategic, coordinated approach to our future aphasia research activities. Many researchers and healthcare professionals in non-English speaking regions will soon be able to use a validated and reliable language assessment tool to collect data or to inform their therapy decisions. We have sought coherence in our use of the term 'aphasia', core outcomes for future aphasia research and supported the development of accessible information materials for people with aphasia. Our dissemination efforts have sought to share our findings with people with aphasia and their families, health and social care professionals and third sector groups supporting people with aphasia. Through these efforts we successfully met the objectives of our Action.

### Acknowledgements

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We thank our Action's Science Officer Dr. Luule Mizera and Administrative Officer Rose Cruz Santos for their invaluable support and assistance during the Action.

Thanks to the members of the Collaboration who contributed to meetings, discussions, project proposals, manuscripts and other activities throughout the Action. Particular thanks to the members of the Executive Committee, the Management Committee members and those who generously hosted working group meetings, training schools, short term scientific missions, workshops and Action conferences.

Our local hosts were responsible for making possible the vibrant and productive exchanges at the heart of the Collaboration's success. Our special thanks to:

Dr Myzoon Ali, Glasgow Caledonian University Dr Charlotte Jacquemot, Ecole Normale Supérieure, France Professor Sue Franklin, University of Limerick, Ireland Dr Ritienne Grima, University of Malta, Malta Dr Evy Visch Brink, Erasmus University Medical Centre, Rotterdam Dr Jytte Isaksen, University of Southern Denmark, Denmark Dr Luis Jesus, University of Aveiro, Portugal Dr Maria Kambanaros, Technological University of Cyprus, Cyprus Dr Tarja Kukkonen, University of Tampere, Finland Dr Madeline Cruice, City, University of London, UK Professor Carlos Hernandez Sacristan, University of Valencia, Spain Dr Valantis Fyndanis, University of Oslo, Norway Dr Mieke van de Sandt-Koenderman, Rijndam Rehabilitation Center & Erasmus University Rotterdam, The Netherlands

We thank our Grant Holder Lorna Kerr and administrative assistants Kathryn VandenBerg and Carole Lindsay. Professor Marian Brady, Lorna Kerr and the Nursing, Midwifery and Allied Health Professions Research Unit are funded by the Chief Scientist Office, Scottish Government, Health and Social Care Directorate. The views expressed here are those of the authors and not necessarily those of the funders.



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# 1. Aims

The COST funded Collaboration of Aphasia Trialists (Action IS1208) aimed to develop and support an international network of collaborators with an interest in aphasia rehabilitation research which would facilitate the conduct of high quality, coordinated aphasia research activities.

- 1. Develop a formal international network of investigators and clinicians from a range of settings and specialist domains with an interest in aphasia rehabilitation research.
- 2. Develop a sustainable web-based application to support the network functions.
- 3. Facilitate members' access to data, resources, consensus statements, expertise and promote knowledge transfer between researchers and settings.
- 4. Foster the development of an international network of coordinated and collaborative research activities which will improve our understanding of the impact of aphasia (on the individual, on families), assessment, diagnosis, prognosis, rehabilitation, recovery and reintegration (functional, rehabilitation, occupational, societal and economic) of people with aphasia.

# 2. Management Committee

### Management Committee

MC Chair	Prof Marian Brady (UK)
MC Vice Chair	Dr Evy G Visch Brink (NL)
WG1 Leader	Dr Myzoon Ali (UK)
WG2 Leader	Prof Spyridoula Varlokosta (GR)
WG3 Leader	Dr Ann Charlotte Laska (SE)
WG4 Leader	Dr Evy G Visch Brink (NL)
WG5 Leader	Dr Madeline Cruice (UK)
STSM Co-ordinator	Professor Sasa Filipovic (RS)
Conference Co-Ordinator	Professor Hanne Gram Simonsen (NO)
Research Officer	Professor Sue Franklin (IE)
Dissemination Officer	Dr Kleanthes Grohmann (CY)
ESR and Training Officer	Dr Ritienne Grima (MT)
Administration Officer	Dr Myzoon Ali (UK)

#### MC Members

Belgium	Prof Luuk Van Waes	Israel	Ms Mali Gil
Belgium	Dr Mariëlle Leijten	Italy	Prof Nicola Smania
Croatia	Dr Jelena Kuvac Kraljevic	Italy	Prof Gianfranco Denes
Croatia	Prof Melita Kovacevic	Lithuania	Dr Ingrida Balciuniene
Cyprus	Prof Fofi Constantinidou	Malta	Dr Ritienne Grima
Cyprus	Prof Kleanthes Grohmann	Netherlands	Dr Evy G Visch Brink
Denmark	Ms Jytte Isaksen	Norway	Prof Hanne Gram Simonsen
Denmark	Dr Lise Randrup Jensen	Norway	Dr Marianne Lind
Finland	Dr Tarja Kukkonen	Portugal	Dr Luís Jesus
France	Dr Charlotte Jacquemot	Portugal	Ms Vânia De Aguiar
France	Dr Efstathia Soroli	Serbia	Dr Jasmina Vuksanovic
Germany	Prof Friedemann Pulvermüller	Serbia	Prof Sasa Filipovic
Germany	Dr Caterina Breitenstein	Spain	Prof Carlos Hernandez-
Greece	Dr Chrysovalantis Fyndanis	Sacristan	
Greece	Prof Spyridoula Varlokosta	Spain	Dr Anna Gavarro Alguero
Hungary	Ms Lilla Zakarias	Sweden	Dr Ann Charlotte Laska
Hungary	Dr Gyula Demeter	Sweden	Prof Elisabeth Ahlsén
Ireland	Prof Sue Franklin	Turkey	Prof İlknur Maviş
Ireland	Dr Caroline Jagoe	UK	Prof Audrey Bowen
Israel	Prof Varda Soskolne	UK	Dr Myzoon Ali

### Near Neigbour Countries MC Observers

Russia	Prof Tatiana Chernigovskaya
Russia	Dr Olga Dragoy
Russia	Prof Alexandr Kornev

#### International Partner Countries MC Observers

Australia	Prof Linda Worrall	
South Africa	Prof Claire Penn	
South Africa	Ms Caitlin Longman	
New Zealand	Dr Tami Howe	

#### MC Substitutes

Belgium	Ms Elise Drijbooms
Croatia	Ms Gordana Hrzica
Croatia	Dr Marijan Palmovic
Cyprus	Dr Maria Kambanaros
Germany	Prof Bettina Mohr
Greece	Prof Alexandra Economou
Greece	Prof Voula Georgopoulos
Greece	Dr Ilias Papathanasiou
Italy	Dr Marialuisa Gandolfi
Lithuania	Dr Laura Kamandulyte
Netherlands	Dr Mieke Van De Sandt
Norway	Ms Monica Knoph
Norway	Prof Kristian Emil Kristoffersen



Fig. 1 Collaboration members at the Final Action Conference, Rotterdam 2017

# 3. Collaborations

"The assessment, diagnosis and rehabilitation of people with aphasia in these regions will have a great opportunity to ameliorate the performance...."

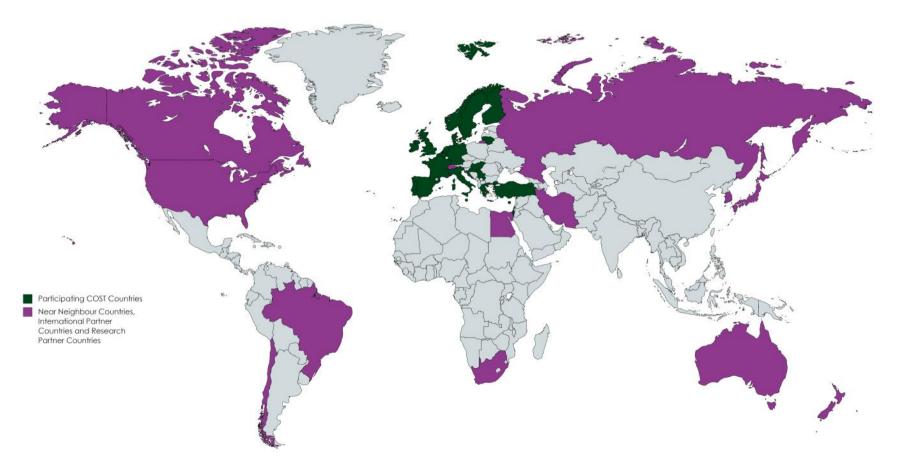


Fig. 2 Participation in the Collaboration of Aphasia Trialists' activities



COST is supported by the EU Framework Programme Horizon H2020

# 4. Working Groups



COST is supported by the EU Framework Programme Horizon H2020

## 4.1 Website development Working Group

"The openness and user-friendliness of the Action website are good...The Action website was an effective means of disseminating the Action."

### **Working Group Members**

Myzoon Ali Kleanthes Grohmann Marielle Leijten Sue Franklin Marian Brady Kathryn VandenBerg

### **Projects**

Development of CATs website www.aphasiatrials.org

The Collaboration of Aphasia Trialists (CATs) website reported Action activities and provided aphasia research resources to an international, multidisciplinary audience of researchers, people with aphasia, clinicians, therapists and students.

At the Action end the website had received 1,929 page views by 738 unique users from the UK (16.5%), Russia (15.2%), the USA (14.6%), Germany, Norway, Spain and Australia. Approximately one third are returning visitors and two thirds are new visitors.





Fig. 3 Pages from the CATs website

### 4.2 Assessments and Outcomes Working Group

"The impact of the development of multilingual adaptations of the Comprehensive Aphasia Test across 14 languages (Basque, Catalan, Croatian, Finnish, French, Greek, Hungarian, Lithuanian, Norwegian, Portuguese, Serbian, Spanish, Swedish and Turkish) is really important from a Scientific and societal point of view."



Fig. 4 Working Group 2 Meeting, Limassol 2015

#### **Working Group Members**

Spyridoula Varlokosta (Lead) Chrysovalantis Fyndanis (Deputy Lead) Ritienne Grima Tarja Kukkonen Jasmina Vuksanovic Carlos Hernandez Sacristan Kleanthes Grohmann Jelena Kuvac Kraljevic Melita Kovacevic Ann Charlotte Laska Ingrida Balciuniene Luuk Van Waes Marielle Leijten Marianne Lind Hanne Gram Simonsen Silvia Martinez Ferriero Io Salmons Vania de Aguiar Jovana Bjekic Lilla Zakarias Efstathia Soroli **Djaina Satoer** Fofi Constantinidou Charlotte Jacquemot Michaela Nerantzini David Howard Elizabeth Armstrong Meghann Grawburg

Luís Jesus Alexandr Kornev Madeline Cruice Monica Blom Johansson **Ioannis Papakyritsis** Lotte Meteyard Lisbeth Haaber Hansen Lucy Dipper Liliana Esgueira dos Santos **Kristina** Thiele Ana Filipa Murteira Amaia Munarriz Majken Kaae Frederiksen Dimitra Skotinou Marie Pourquie Seckin Arslan Tatiana Chernigovskaya Anne Whitworth Simon Horton Ingrid Sör Klaudia Ceder Anna Stielow Sviatlana Karpava Mariya V. Khudyakova Elena Peristeri Ljiljana Lazarevic Anastasia Linnik Anna Gavarró

Julie Morris Kati Renvall Adria Rofes Marina Langanaro Laura Bos Cathy Price Maria Kambanaros Liliana Esgueira dos Santos Byurakn Ishkhanyan Müge Tunçer Ilknur Mavis

### **Assessments and Outcomes - Projects**

Cross-linguistic adaptations of the Comprehensive Aphasia Test (CAT) into

- Basque (Section 7.1 Project No. 6)
- Catalan (Section 7.1 Project No. 7)
- Croatian (Section 7.1 Project No. 8)
- Finnish (Section 7.1 Project No. 9)
- French (Section 7.1 Project No. 10)
- Greek (Section 7.1 Project No. 11)
- Hungarian (Section 7.1 Project No. 12)
- Norwegian (Section 7.1 Project No. 13)
- Portuguese (Section 7.1 Project No. 14)
- Serbian (Section 7.1 Project No. 15)
- Spanish (Section 7.1 Project No. 16)
- Swedish (Section 7.1 Project No. 17)
- Turkish (Section 7.1 Project No. 18)

.

Adaptation of the Verb and Sentence Test into Russian (Section 7.1 Project No. 27)

## 4.3 Predictors and Prognosis Working Group

The participation to the RELEASE (REhabilitation and recovery of people with Aphasia after StrokE) project is really important for the relevance and the significance of the impact. The project is still ongoing and involves collaborators from 24 countries (and more than 5.500 individual patient datasets)



Fig. 5 Working Group Meeting, Tampere 2016

### **Working Group Members**

Ann Charlotte Laska (Lead)			
Myzoon Ali (Deputy Lead)			
Marian Brady			
Valantis Fyndanis			
Spyridoula Varlokosta			
Tarja Kukkonen			
Ingrida Balciuniene			
Retienne Grima			
Jelena Kuvac Kraljevic			
Sasa Filipovic			
Jasmina Vuksanovic			
Marialuisa Gandolfi			
Frank Becker			
Marko Zivanovic			

Michaela Nerantzini Caterina Breitenstein Jelena Kuvac Kraljevic Adi Lifshitz Ben Basat David Copland Hedda Døli Cathy Price Helene Killmer Holly Robson Gyula Demeter Andrew Elders Hellmuth Obrig

### **Predictors and Prognosis - Projects**

- Systematic review of the factors predicting language recovery in individuals with post-stroke aphasia (in progress)
- REhabilitation and recovery of peopLE with Aphasia after StrokE (RELEASE) (Section 7.1 Project No. 4)
- International Population Registry of Aphasia after StrokE (I-PRAISE) (in development)

## 4.4 Effectiveness of interventions Working Group

"The strategic and coordinated approach to future aphasia research activities is clear in the ten aphasia research priorities. If the CATs network is able to pursue these priorities and respond to each of them over the next two years, the result is of real value."



Fig. 6 Working Group 4 Meeting, Tampere 2016

### Working Group Members

Evy Visch-Brink (Lead)	Femke Nouwens
Tarja Kukkonen (Deputy Lead)	Kati Renvall
Friedmann Pulvermuller	Miranda Rose
Melita Kovacevic	Anne Whitworth
Marian Brady	Ingrid Berhns
Jasmina Vuksanovic	Sue Franklin
Spyridoula Varlokosta	Lucy Dipper
Audrey Bowen	Wendy Best
Sasa Filipovic	Annette Baumgaertner
Mali Gil	Stefanie Abel
Gianfranco Denes	Ioannis Papakyritsis
Melanie Kirmess	Marcus Meinzer
Pam Enderby	Madeleine Harrison
David Howard	Katerina Hilari
Mieke van de Sandt Koenderman	Lisbeth Frølund Kristensen
Monica I Knoph	Kris McGill
Michaela Nerantzini	Louise Williams
Carolina Mendez Orellana	Jaime Monreal

### **Effectiveness of interventions – Projects**

- AsPIRE: Aphasia Intervention description in Research (Section 7.1 Project No. 23)
- Inventory clinical practice aphasia treatment: i-CLIP (Section 7.1 Project No. 21)
- RELEASE: REhabilitation and recovery of peopLE with Aphasia after StrokE: Utilizing secondary data to enhance speech and language therapy interventions for people with aphasia after stroke (Section 7.1 Project No. 4)
- Aphasia Research Priorities (Section 7.1 Project No. 22)
- Aphasia telerehabilitation early post stroke [PhD Fellowship] (Section 7.1 Project No.
   3)

### 4.5 Societal Impact and Reintegration Working Group

"...a shared definition could have important consequences for people with aphasia in clinical and research contexts and would strengthen collaborative working across a range of multidisciplinary and research paradigms."



Fig. 7 Working Group 5 Meeting, Dublin 2014

### **Working Group Members**

Madeline Cruice (Lead) Jytte Isaksen (Deputy Lead) Caroline Jagoe Linda Worrall Lise Randrup Jensen Elisabeth Ahlsen Audrey Bowen **Gianfranco Denes** Varda Soskolne Gabriele Kitzmuller Karianne Berg **Carole Pound** Line Haaland- Johansen Nada Zemva Gill Pearl Simon Horton

Shirley Thomas Maria da Assunção Coelho de Matos Brigida Patricio Luís Jesus Suzanne Beeke Tami Howe Ruth Mc Menamin Caitlin Brandenburg Ciara Shiggins Fiona Menger Dafna Olenik Shirley Thomas Luis Jesus Caitlin Longman Sarah Wallace

### **Societal Impact and Reintegration - Projects**

- Asset-based Community Development (ABCD) (Section 7.1 Project No. 5)
- Meaningful Evaluation in AphaSia in REhabilitation and Society (MEASURES) (Section 7.1 Project No. 20)
- Supporting Communicative Participation of Individuals with Aphasia (Section 7.1 Project No. 1)
- "What can I do for you?" A visual communication guide for health care workers who are treating people with aphasia (Section 7.1 Project No. 2)
- Definition of Aphasia. (Section 7.1 Project No. 19)
- Do stroke outcome measures capture outcomes for people with aphasia (Section 7.1 Project No. 24)

5. Achievement of Memorandum of Understanding objectives

"...the expected goals and impacts have been achieved"

The Action reported the achievement of the following objectives and their dependence on the Action networking.

N	lemorandum of Understanding Objective	Level of achievement reported by Action	Dependence reported by Action
1.	Develop a formal international network of		
	investigators and clinicians from a range of settings	76 - 100%	High
	and specialist domains with an interest in aphasia		
	rehabilitation research		
2.	Develop a sustainable web-based application to	76 - 100%	High
	support the network functions		
3.	Facilitate members access to data, resources,		
	consensus statements, expertise and promote	76 - 100%	High
	knowledge transfer between researchers and		
	settings		
4.	Foster the development of an international network		
	of coordinated and collaborative research activities		
	which will improve our understanding of the impact of		
	aphasia (on the individual, on families), assessment,	76 - 100%	High
	diagnosis, prognosis, rehabilitation, recovery and		
	reintegration (functional, rehabilitation, occupational,		
	societal and economic) of people with aphasia		

Key: MoU = Memorandum of Understanding; Dependence = dependence of the achievement (of each MoU objective) on the Action networking. % = percentage.

## **Objectives**

1. Develop a formal international network of investigators and clinicians from a range of settings and specialist domains with an interest in aphasia rehabilitation research

Our Action network developed from 13 original proposers to include 179 multidisciplinary aphasia researchers from 26 counties including Action COST Inclusiveness Target Countries of Cyprus [CY], Croatia [HR], Hungary [HU], Lithuania [LT], Malta [MT], Portugal [PT], the Republic of Serbia [RS] and Turkey [TR], the COST Near Neighbour Country Russia [RU] and the International Partner countries Australia [AU], New Zealand [NZ] and South Africa [SA].

Through our various research activities our project networks also included aphasia researchers from an additional 9 countries;

- Brazil [BR]
- Canada [CA]
- Chile [CL]
- Egypt [EP]
- Iran [IR]
- Japan [JP]
- North Korea [KR]
- Switzerland [CH]
- United States of America [US]

Our network has been strengthened by a broad range of relevant multidisciplinary experts in linguistics, neuropsychology, speech and language therapy, neurology, rehabilitation, statistics, stroke medicine, neuroscience, anthropology, and audiology. (<u>http://www.aphasiatrials.org/</u>).

Across the network membership we quickly became aware of the wide range of challenges in the provision of clinical service for people with aphasia and their families across the participating COST countries. Differential approaches to service organisation, provision and accessibility were in evidence. Poor availability of valid and reliable aphasia assessment tools in different languages continues to be a particular challenge for many non-English speaking regions, while the different professional backgrounds of therapy providers in different regions is also an important consideration.

Our Action sought to support the development of Early Career Investigators (within eight years of their PhD) and junior researchers. In our field of science many of these junior researchers are at pre-doctoral levels (PhD candidates) and we felt it was important to include them in our network. For example, our working groups were led by a senior researcher with the support of a more junior Early Career Investigator as a Deputy Lead for each group thus developing leadership capacity in this field.

Despite the broad range of geographical regions, disciplinary perspectives, scientific paradigms, languages and local clinical service provision challenges evident across our membership, we quickly became aware that we had a shared ambition to improve the rehabilitation and recovery of people with aphasia after stroke.

### 2. Develop a sustainable web-based application to support the network functions

Each of the Working Group pages on our website profiled the research activities ongoing within that Working Group –for example the list of aphasia assessment language adaptations underway within Working Group 2 were listed: <a href="http://www.aphasiatrials.org/index.php/working-groups/assessment-and-outcomes/assessment-and-outcomes-research">http://www.aphasiatrials.org/index.php/working-groups/assessment-and-outcomes/assessment-and-outcomes-research</a>

In addition, each profile had the capacity to host an Action research project-specific page. For example our National Institute for Health Research (UK) funded RELEASE project pages provided an overview of our project aims and objectives, our collaborators and our project newsletters:

http://www.aphasiatrials.org/index.php/working-groups/prognosispredictors/research/2-uncategorised/137-rehabilitation-and-recovery-of-peoplewith-aphasia-after-stroke-release

Our website communicated information on:

- funding to support Short Term Scientific Missions <u>http://www.aphasiatrials.org/index.php/research-and-training/stsms</u>,
- CATs conference registration, abstract submissions, programme and abstract book
- Training School attendance
- Workshop participation
- Publications
- Funding awards
- Action Meetings

Similarly, reports on these activities (STSMs reports, poster presentations and conference presentations, meeting minutes) were available to members via the website. Our website also highlighted on-going randomised controlled trials of interventions for people with aphasia after stroke:

http://www.aphasiatrials.org/index.php/research/current-aphasia-trials.

Our website and its success has significantly benefited from the establishment of a dedicated Working Group (Section 4.1).

### 3. Facilitate members access to data, resources, consensus statements, expertise and promote knowledge transfer between researchers and settings

Within each of the Working Group profiles our website provided space to host Action research project-specific information – for example our RELEASE project pages provided an overview of our project collaborators, our aims and objectives and our project newsletters <u>http://www.aphasiatrials.org/index.php/workinggroups/prognosis-predictors/research/2-uncategorised/137-rehabilitation-andrecovery-of-people-with-aphasia-after-stroke-release</u>

Importantly our website has facilitated data sharing activities

http://www.aphasiatrials.org/index.php/research/aphasia-datasets. Data contributors uploaded their electronic datasets via a secure portal which enabled data sharing with the RELEASE research team. Following the end of the RELEASE project (June 2018) a legacy CATs database will underpin the development of further research using pre-existing aphasia data for secondary analysis. We envisage our www.aphasiatrials.org website will continue to have a key role in facilitating further data sharing, feasibility searches and information requests. In this way Collaboration members will be able to seek access to this important pre-existing aphasia trial data resource for novel secondary data analyses.

Our website communicated opportunities to apply for funding to support Short Term Scientific Missions <u>http://www.aphasiatrials.org/index.php/research-and-training/stsms</u>.

Our website supported CATs conference abstract submissions (for presentations and posters). Similarly, STSM reports and copies of poster presentations and conference presentations were available to members via the website.

We collated and shared links to international clinical guidelines on stroke and aphasia and aphasia best practice statements to support the highest quality of service delivery for people with aphasia across our network <a href="http://www.aphasiatrials.org/index.php/aphasia-resources/links/international-stroke-and-aphasia-guidelines">http://www.aphasiatrials.org/index.php/aphasia-resources/links/international-stroke-and-aphasia-guidelines</a> . We also facilitated access to multilingual versions of information on aphasia.

4. Foster the development of an international network of coordinated and collaborative research activities which will improve our understanding of the impact of aphasia (on the individual, on families), assessment, diagnosis, prognosis, rehabilitation, recovery and reintegration (functional, rehabilitation, occupational, societal and economic) of people with aphasia

Our Action supported the development of an international network of researchers across 35 countries that collaborated to bridge different disciplinary, language and national perspectives to identify a shared focus on enhancing the rehabilitation and recovery of people with aphasia after stroke.

During this process we highlighted our shared perspectives and ambitions for the future of aphasia research. We sought to improve consistency in the use of aphasia terminology and we supported the development of consensus on core outcomes for aphasia research.

Our Action our members have developed 36 ongoing research projects and 11 research proposals. Some research projects are supported by the members' academic institutions while others have secured external research project grant income in excess of €1,1 million. These grants were typically from national funders. An additional 11 project proposals are currently under review or were unsuccessful (including two H2020 applications that were highly rated).

Amongst these research activities there are some striking examples of synergistic development of complementary projects. Working Group 2 (WG2) supported the adaptation of the Comprehensive Aphasia Test

(https://www.routledge.com/Comprehensive-Aphasia-Test/Swinburn-Porter-Howard/p/book/9781841693798) across 14 languages (Basque, Catalan, Croatian, Finnish, French, Greek, Hungarian, Lithuanian, Norwegian, Portuguese, Serbian, Spanish, Swedish, Turkish). Each project was undertaken within nationally based research teams where a range of language and cultural-specific issues were addressed. Much efficiency in the research activities was gained through Working Group 2 members' coordination of effort and simultaneous adaptation of a single tool across multiple languages. Their sharing of methodological expertise and resources (e.g. pictures to stimulate language production) were vital to the efficiency and effectiveness of this endeavour.

Access to a shared assessment tool that can be used across regions and languages is a significant development and will support the feasibility of collaborative international aphasia research - supporting for example multi-national, multi-site, shared data collection or facilitating meta-analyses of secondary dataset. The clinical benefits of therapists having access to robustly developed comprehensive aphasia language assessment tools for non-English languages (where previously few existed) will also be significant for people with aphasia and their families.

## **Capacity Building**

"My participation in the CAT's training school in May 2014 was a fantastic experience! I had the opportunity to attend very interesting lectures given by scholars who are international experts in their field.... interacted with both junior and senior colleagues from different backgrounds. ...it allowed me to learn new things and enhance my skill set, including grant writing/extra-mural funding attraction and networking skills, which are really important for early stage researchers!"

> Dr Chrysovalantis Fyndanis University of Potsdam, Germany University of Athens, Greece

# 6. Training Schools

Throughout the course of the Action Dr Ritienne Grima took the lead role in the development and hosting of the Training School Programme for the Collaboration. Her inclusive approach to identifying training school topics that reflected the needs of early stage researchers, her considerable organisational skills in arranging the training schools (often in challenging logistical contexts) and her accomplished hosting of these events were very much appreciated by the Executive Committee, the Collaboration members and particularly the Training School Participants with consistently high ratings on the feedback following the events.

### 2014 Training School Programme

#### Aphasia Research and Methodology: From Idea to Dissemination

The first Collaboration Training School sought to share best research practice with junior and early stage aphasia researchers. Experienced research leaders shared their expertise in the process of developing aphasia research questions, choosing suitable methodologies and the preparation of competitive grant applications. The programme varied from formal teaching sessions to a grant development clinic where experienced researchers supported the development of future grant application ideas. We also considered the latest materials and templates to support the participation of people with aphasia in the research process. Participants had the opportunity to meet with Iveta Simera from the Equator Network, a key reference to reporting guidance and other research resources relevant to the conduct and high quality reporting of aphasia research activities.

The three day programme included the following sessions:

Developing and refining research questions; Identifying gaps in the evidence; Reviews and systematic reviews; Research design and selecting appropriate methodologies; Recruitment issues (including ethical inclusion & developing aphasia accessible information sheets & consent forms); Writing Grant Applications; Grant Writing Workshop; Identifying opportunities for EU funding; Paper Writing; Writing Toolkit; Question & Answer/ Individual Project Advice

#### Trainers:

Prof Brian Williams; Prof Marian Brady; Mrs Gill Pearl; Ms Martina Pace; Dr Iveta Simera

#### **2015 Training School Programme**

#### The International Classification of Functioning, Disability and Health and Aphasia Research

This intensive and interactive masterclass for researchers who were interested in using the World Health Organisation's International Classification of Functioning, Disability and Health in aphasia research and targeted both early stage and experienced aphasia researchers. The broad aims of the ICF as a conceptual framework and classification system were presented by esteemed researchers in the field. Findings from the aphasia research literature that has used the ICF were presented and a future research agenda brainstormed in a group discussion format using the Nominal Group Technique for consensus approaches. Skills training in cross walking assessment items from more specific assessments of components of the ICF were provided. Participants also learned how to reliably classify content units from transcripts of interviews with people with aphasia.

Three day programme which included sessions on the following topics:

ICF Core sets; Why is the ICF important in aphasia research?; How has the ICF been used in aphasia research to date?; Beyond the ICF: Quality of life in aphasia; Aphasia assessments and therapy and the ICF; Research training: crosswalking assessment items to the ICF; Research training: quality of life measures for people with aphasia; Qualitative methods and the ICF; Research training: Content analysis of transcripts of aphasic language; Research training: Coding transcript content with the ICF; Research training: Developing a research agenda for aphasia using the ICF: what don't we know? An illustration of the Nominal Group Technique; Promoting the ICF in CAT: a group discussion and an action plan, post evaluation.

#### Trainers:

Prof Linda Worrall; Dr Mieke Van de Sandt; Dr Katerina Hilari; Dr Sarah Wallace; Dr Tami Howe; Dr Jytte Isaksen

#### 2016 Training School Programme

#### Statistical Methods for Aphasia Researchers

Following a poll of the Junior and Early Stage Researchers across the Collaboration the most identified need for additional training was on the topic of statistical approaches suitable for aphasia research. A range of statistical methodologies were addressed including randomised

controlled trials, meta-analyses, case series, non-randomised comparative studies and psychometric testing.

Three day programme which included sessions on the following topics:

Introduction and overview of different statistical methods; introduction to randomised controlled trials; designing and analysing RCTs of aphasia interventions; challenges and issues involved in setting up and conducting a large aphasia trial; history of meta-analysis; Single case studies and case series of treatment; single case studies and meta-analysis of single case studies using random forests, with examples from aphasia research; group studies in aphasia research and mixed effects models with logistic data; design, psychometric testing and validation of outcome measures for aphasia; practical sessions in statistical software.

#### Trainers:

Prof Jon Godwin; Mr Andrew Elders; Prof David Howard; Dr. Femke Nouwens; Dr Vania de Aguiar



Fig. 8 Training School participants, Malta 2016

# 7. Short Term Scientific Missions

"The STSM provided a unique opportunity for me to visit the Neurocognition of Language Group in Potsdam, Germany. During my stay, we discussed the most appropriate method of data analyses of a previously conducted case study in Hungary and exchanged ideas about future potential collaborative research. It is easy and smooth to apply for a STSM, with a fast decision procedure, allowing for visiting anybody working on aphasia in one of the participating COST countries. For me, it was a once in a lifetime experience."

> Lilla Zakariás Eötvös Loránd University, Budapest

Prof Sasa Filipovic together with the support of Dr Myzoon Ali and the STSM committee coordinated the Short Term Scientific Missions (STSMs) across the Action. A total of 17 STSMs were awarded and full reports from all STSMs can be downloaded from the <u>Collaboration of</u> <u>Aphasia Trialists website</u>.

STSM	Name	STSM Title	Host Institution	Dates of Visit
1.	Kleanthes Grohmann	The development of an aphasia assessment battery for Cypriot Greek	University of Athens	10-14th Feb 2014
2.	Lilla Zakarias	Integrating cognitive principles into language therapy	University of Potsdam (Potsdam, Germany),	1-24th Feb 2014
3.	Madeline Cruice	Transforming clinical practices in exploring the impact of living with aphasia	University of Southern Denmark	13-17th Jan 2014
4.	Maria Kambanaros	The development of an aphasia assessment battery for Cypriot Greek	University of Athens	10-14 Feb 2014
5.	Pauline Campbell	Hearing disorders in post- stroke aphasia: Impact on diagnosis and rehabilitation	Erasmus University Medical Centre	23 Feb-1st Mar 2014
6.	Voula Georgopoulos	The Development of Intelligent Decision Support Tools for Aphasia Assessment	Cyprus University of Technology	22-26th Sept 2014
7.	Yulia Akinina	Adaptation of the VAST to the Russian language	University Groningen	1-30th Oct 2014
8.	Helen Kelly	Development of skills in designing rehabilitation research using eye-tracker	Queen Margaret University	3-12th Dec 2014

#### **STSMs Awards**

STSM	Name	STSM Title	Host Institution	Dates of Visit
9.	Jasmina Vuksanovic	Finalizing the systematic review article on factors predicting language recovery in individuals with post-stroke aphasia	Karolinska Institute	1-18th Feb 2015
10.	Ingrid Behrns	The writing process in persons with acquired writing difficulties	University of Antwerp	6-11th Sep 2015
11.	Caitlin Longman	The effect of the environment on the elderly living with and without aphasia in Johannesburg	University of the Witwatersrand, South Africa	4-15th Jan 2016
12.	Karianne Berg	Establishing consensus statements around an updated definition of aphasia	University of Queensland	6-28th Feb 2016
13.	Adria Rofes	Development of a single-case EEG paradigm to assess language in people with aphasia after stroke	Maastricht University	17-31st Jan 2016
14.	Valantis Fyndanis	Writing up the article Cross-linguistic adaptations of The Comprehensive Aphasia	University of Athens	13-26th Nov 2016
15.	Hege Prag Ora	Aphasia telerehabilitation early post stroke	Glasgow Caledonian University	5-12th Dec 2016

STSM	Name	STSM Title	Host Institution	Dates of Visit
16.	Tarja Kukkonen	How is the ICF grid manifested in current aphasia research	Glasgow Caledonian University	4-14th Dec 2016
17.	Helene Killmer	Development of skills in analysing conversations of people with aphasia	University College London	5-11th March 2017

# 8. Workshops

"...good involvement of different researchers and aphasia groups" COST Action Rapporteur 2017 The following workshops were co-ordinated or led by collaborators between 2013-2017.

#### **External Workshops**

**1. Workshop** at the Aphasia United Conference, Coventy, UK. March 5th & 6th 2017 for people with aphasia and their families.

#### Asset-based approaches.

Ruth McMenamin [IE] and Ciara Shiggins [UK].

In conversation with people with mild to severe aphasia the workshop leads were able to pilot the feasibility of having "asset-based" conversations with people who have aphasia using supported communication techniques. Questions such as "what keeps you well?" or "what helps you to live successfully with aphasia?" were employed to elicit the views of people with aphasia. Flexible use of the supporting materials and activities were required. Analysis of these data highlighted different themes of what helped people live well with aphasia. The workshop leads also discussed with people the optimum timing of asset based approaches - in hospital or at home. People with aphasia indicated a preference for such conversations to happen early in the stroke trajectory. This information will be important in the development of feasible interventions that are timely and acceptable for people with aphasia and their families.

2. Workshop at the International Aphasia Rehabilitation Conference (IARC). London. December 14th- 16th, 2016 for international speech and language therapists, aphasia researchers, family members and other healthcare professionals.

## Towards an asset-based approach to living with aphasia: exploring the relevance and implications for people with aphasia and families.

Horton, S [UK], Pearl, G [UK], Soskolne, V [IL], Olenik, D [IL], Haaland-Johansen, L [NO], Isaksen, J [DK], Jagoe, C [IE], Shiggins, C [UK].

The workshop leaders gained opinions and perspectives on the potential use of asset-based approaches as an intervention to support aphasia rehabilitation and recovery. The workshop participants discussed the feasibility of this approach in clinical settings and the implementation of such approaches in their stroke services and settings which is important for the future of this research activity. The therapists reported that they felt this approach could be beneficial and that they could use it in practice to help sustain and maintain wellbeing.

**3.** Workshop at the 5th Novi Sad Workshop on Psycholinguistic, Neurolinguistic and Clinical Linguistic Research, April 2017, Novi Sad, Serbia.

### Which factors predict agrammatic comprehension of Wh-questions in Turkish and German individuals with aphasia?

Seçkin Arslan [DE], Eren Gür [TR], Claudia Felser [DE]

http://digitalna.ff.uns.ac.rs/sadrzaj/2017/978-86-6065-417-7

**4. Workshop** 5th Novi Sad Workshop on Psycholinguistic, Neurolinguistic and Clinical Linguistic Research, April 2017, Novi Sad, Serbia.

### Prepositions in Spanish-speaking individuals with aphasia: Evidence from connected discourse.

Silvia Martínez Ferreiro [NL], Byurakn Ishkhanyan [DK], Kasper Boye [DK].

**5.** Workshop 5th Novi Sad Workshop on Psycholinguistic, Neurolinguistic and Clinical Linguistic Research, April 2017, Novi Sad, Serbia.

#### Effect of language therapy on receptive language recovery in patients with acute aphasia.

Jasmina Vuksanović [RS], Tanja Milovanović [RS], Ljubica Konstantinović, Saša R Filipović [RS]

6. Workshop at the 5th Novi Sad Workshop on Psycholinguistic, Neurolinguistic and Clinical Linguistic Research, April 2017, Novi Sad, Serbia.

#### Differential decay of cognitive abilities and language in healthy elderly population.

Ana Rendulić [HR], Melita Kovačević [HR], Marijan Palmović [HR].

#### 7. Workshop

#### Training on stroke, aphasia and facilitating communication amongst people with aphasia.

#### Caitlin Longman [ZA]

Two stroke workshops were attended by nurses (n=36) and healthcare workers (n=3). The workshops took place at a Johannesburg Non-Governmental Organisation and frail care facility. The training included information about stroke, recognition of stroke symptoms, challenges experienced by people after a stroke and supporting communication with people who had aphasia following their stroke.

#### **CATs Writing Workshops**

#### 1. 23rd-25th November 2016, Athens, Greece

Hosted by the Norwegian Institute in Athens, this workshop enabled working group members to collaborate on CATs Action publications.

#### 2. 2nd-4th November 2015, Copenhagen, Denmark

A writing workshop and publication masterclass designed for aphasia researchers, led by Prof Nina Simmons-Mackie and Prof Chris Code. This was an opportunity for Early Stage Researchers to develop journal articles with one to one guidance from editors of aphasia journals.

Nina Simmons-Mackie, Ph.D., CCC/SLP, BC-ANCDS, is President of AphasiaAccess and is Professor and Scholar in Residence in Communication Sciences and Disorders at Southeastern Louisiana University; associate investigator at the Centre for Clinical Research Excellence in Aphasia Rehabilitation in Australia, and research consultant at the Aphasia Institute in Toronto. She is a recipient of the Honors of the American Speech-Language-Hearing Association. Prof. Simmons-Mackie is one of the founding members of the Academy of Neurologic Communication Disorders and Sciences (ANCDS) and is board certified by ANCDS. She has over 100 professional publications and is an editor of "Supporting Communication for Adults with Acute and Chronic Aphasia".

Chris Code is Professorial Research Fellow in the School of Psychology, Foundation Professor of Communication Sciences and Disorders (Hon) at the University of Sydney, Visiting professor University of Louisianna at Lafayette and used to be Research Manager for Speakability, the British lobbying and advocacy charity for aphasic people conducting research into the psychosocial consequences of aphasia and is Speakability's National Adviser on Aphasia. He is Patron of AphasiaNow. He is co-founding Editor of the international journal Aphasiology, past Editor of the International Journal of Language & Communication Disorders and the Australian Journal of Communication Disorders, and is on the editorial boards of several journals.

#### 3. 29th April- 1st May 2015, Glasgow, UK

Our first Writing Workshop welcomed James C. Coyne, the 2015 Carnegie Centenary Visiting Professor at University of Stirling. He is also Professor Emeritus of Psychology in Psychiatry at University of Pennsylvania where he was Director of Behavioral Oncology at the Abramson Family Cancer Center and Senior Fellow, Leonard Davis Institute of Health Economics. He is currently Professor of Health Psychology at University of Groningen, the Netherlands. He is the author of over 350 articles and chapters and has been identified by ISI Web of Science as one of the most cited psychologists and psychiatrists in the world.

The workshop examined new and old routes to dissemination, strategies for successful submission and post-publication promotion.

# 9. Projects resulting from Action activities

"Action members have developed a portfolio of 27 collaborative aphasia research activities which benefited from the Action support. Most of them are significant from the aphasia point of view." COST Action Rapporteur 2017

# Projects

The Action reported the following projects resulting from Action activities involving at least one Action participant, and for which the Action networking was necessary. In addition the Action reported 12 proposals resulting from Action activities involving at least one Action participant, and for which the Action networking was necessary.

Project title	Main proposer	Funder
<ol> <li>Supporting communicative participation of individuals with aphasia. Lise R. Jensen [DK], Elisabeth Ahlsén [SE], Madeleine Cruice [UK], Simon Horton [UK], Carole Pound [UK]; Jytte Isaksen [DK], Monica Blom-Johansson [SE], Nina Simmons- Mackie [US].</li> </ol>	Lise R. Jensen	National
2. What can I do for you? A visual communication guide for health care workers who are treating people with aphasia. Gabriele Kitzmüller [NO], Karianne Berg [NO], Line Haaland Johansen, [NO], Dafna Olenik [IL]	Gabriele Kitzmüller	National
<ol> <li>Aphasia telerehabilitation early post stroke</li> <li>(PhD Fellowship). Hege Prag Øra [NO], Frank Becker</li> <li>[NO], Melanie Kirmess [NO], Marian Brady [UK]</li> </ol>	Hege Prag Øra [NO]	National

Project title	Main proposer	Funder
4. REhabilitation and recovery of peopLE with Aphasia after StrokE (RELEASE). Marian Brady [UK], Myzoon Ali [UK], Ann-Charlotte Laska [SE], Audrey Bowen [UK], Cathy Price [UK], David Howard [UK], Erin Godecke [AU], Evy Visch-Brink [NL], Jacqueline Hinckley [US], Katerina Hilari [UK], Linda Worrall [AU], Shirley Thomas [UK], Rebecca Palmer [UK], Tarja Kukkonen [FI], Simon Horton [UK], Brian MacWhinney [US], Aura Kagan [CA], Andrew Elders [UK], Jon Godwin [UK], Caterina Britenstein [DE], Frank Becker [NO]	Marian Brady	National
5. Asset-based approaches for stroke survivors with aphasia: promoting and sustaining well-being in the long- term. Simon Horton [UK], Gill Pearl [UK] Varda Soskole [IL], Dafna Olenik [IL], Line Haaland- Johansen [NO], Jytte Isaksen [DK], Caroline Jagoe [IE], Ciara Shiggins [UK]	Horton S	National
<ol> <li>Cross-linguistic adaptations of the</li> <li>Comprehensive Aphasia Test (CAT) into Basque.</li> <li>Amaia Munarriz [ES] Marie Pourquié [ES]</li> </ol>	Amaia Munarriz	Other
<ul> <li>7. Cross-linguistic adaptations of the</li> <li>Comprehensive Aphasia Test (CAT) into Catalan.</li> <li>Anna Gavarró [ES], Adrià Rofes [PT]</li> </ul>	Anna Gavarró	Other

Project title	Main proposer	Funder
8. Cross-linguistic adaptations of the Comprehensive Aphasia Test (CAT) into Croatian. Jelena Kuvac Kraljevic [HR], Melita Kovacevi [HR].	Jelena Kuvac Kraljevic	Other
<ol> <li>Cross-linguistic adaptations of the</li> <li>Comprehensive Aphasia Test (CAT) into Finnish.</li> <li>Taina Kannosto- Blomqvist [FI]; Piia Aro-Pulliainen</li> <li>[FI] Kati Renvall [FI], Minna Laakso [FI], Tarja</li> <li>Kukkonen [FI]</li> </ol>	Tarja Kukkonen	Other
10. Cross-linguistic adaptations of the Comprehensive Aphasia Test (CAT) into French. Efstathia Soroli [FR], Charlotte Jacquemont [FR]	Efstathia Soroli	Other
<ol> <li>Cross-linguistic adaptations of the Comprehensive Aphasia Test (CAT) into Greek.</li> <li>Spyridoula Varlokosta [GR], Kleanthes Grohmann [CY], Valantis Fyndanis [GR], Michaela Nerantzini [GR], Ioannis Papakyritsis [GR], Maria Kambanaros [CY]</li> </ol>	Spyridoula Varlokosta	Other
<ol> <li>Cross-linguistic adaptations of the</li> <li>Comprehensive Aphasia Test (CAT) into Hungarian.</li> <li>Lilla Zakariás [HU], Ágnes Lukács [HU]</li> </ol>	Lilla Zakariás	Other
<ol> <li>Cross-linguistic adaptations of the</li> <li>Comprehensive Aphasia Test (CAT) into Norwegian.</li> <li>Marianne Lind [NO], Hanne Gram Simonsen [NO]</li> </ol>	Marianne Lind	Other
14. Cross-linguistic adaptations of the Comprehensive Aphasia Test (CAT) into Portuguese. Luís Jesus [PT]	Luis Jesus	Other

Project title	Main proposer	Funder
15. Cross-linguistic adaptations of the Comprehensive Aphasia Test (CAT) into Serbian. Jasmina Vuksanović [RS], Jovana Bjekić [RS]	Jasmina Vuksanović	Other
16. Cross-linguistic adaptations of the Comprehensive Aphasia Test (CAT) into Spanish. Carlos Hernández Sacristán [ES], Silvia Martínez- Ferreiro [ES], Carolina Méndez- Orellana [ES]	Carlos Hernández Sacristán	Other
<ul><li>17. Cross-linguistic adaptations of the</li><li>Comprehensive Aphasia Test (CAT) into Swedish.</li><li>Monica Blom Johansson [SE], Ingrid Sör [SE], Klaudia</li><li>Ceder [SE]</li></ul>	Monica Blom Johansson	Other
18. Cross-linguistic adaptations of the Comprehensive Aphasia Test (CAT) into Turkish [Kapsamli Afazi Testinin Testinin Türkçeye Uyarlanmasi ve Diger Afazi Degerlendirme Araçlarinin Gelistirilmesi] İlknur Maviş [TR], Aylin Müge Tunçer [TR]	İlknur Maviş	Other
19. Definition of Aphasia. Karianne Berg [ NO], Linda Worrall [AU]	Karianne Berg	Other
20. MEASURES: Meaningful Evaluation in AphaSia in REhabilitation and Society. Sarah Wallace [AU], Madeline Cruice [UK], Luis Jesus [PT], Maria da Assunção Coelho de Matos [PT], Sarah Wallace [AU], Caroline Jagoe [IE], Tanya Rose [AU], Caitlin Brandenburg [AU], Linda Worrall [AU]	Sarah Wallace	Other

Project title	Main proposer	Funder
21. International Survey of Access to SLT for people with aphasia after stroke. Sue Franklin [IE] Evy Visch-Brink [NL], Mieke van de Sandt- Koenderman [NL], Femke Nouwens [NL], Carolina Mendez [NL].	Sue Franklin	Other
22. Top Priorities for Aphasia Research. Sue Franklin [MC, WG4, IE], Dearbhla Harhen[IE], Michelle Hayes[IE], Sasha McManus[IE], Alex Pollock [UK]	Sue Franklin	Other
23. AsPIRE: APhasia Intervention description in REsearch. Evy Visch- Brink [NL], Tarja Kukkonen [MC, WG4 Deputy Lead, FI], Monica Knoph [NO], Mali Gil [IS], Wendy Best [UK], Franco Denes [IT], Miranda Rose [AU], Femke Nouwens [NL], Mieke van de Sandt- Koenderman [NL], Lucy Dipper [UK], Alexandr Kornev [RU], Marian Brady [UK].	Evy Visch-Brink	Other
24. Do stroke rehabilitation outcome measures capture outcomes for people with aphasia? Winsome Li [AU], Linda Worrall [AU], Sarah Wallace [AU], Marian Brady [UK]	Linda Worrall	Other
25. Cross-linguistic adaptations of the Western Aphasia Battery (Revised), the Scenario Test and the Stroke and Aphasia Quality Of Life (SAQOL)-39	Caterina Breitenstein	National
26. Erasmus+ Internship Program to from Turkey İlayda Kıncal [TU] to Glasgow Caledonian University [UK]	İlayda Kıncal	Erasmus+ Internship Program
27. Adaptation of the Verb and Sentence Test (VAST) to Russian. Yulia Akinina [RU], Roelien Bastiaanse [NL]	Yulia Akinina	Other EU - COST STSM

# 10. Publications resulting from Action activities

"In most of the outputs is really clear that the network has put together ideas, research projects and the use of different perspectives to create projects and proposals in the aphasia field."

COST Action Rapporteur 2017

# **Publications**

Sixteen publications on the topic of the Action that were co-authored by at least two Action participants from two countries participating in the Action, and for which the Action networking was necessary are listed below. An additional 6 papers in preparation are also listed.

1. Brady MC, Ali M, Fyndanis C, Kambanaros, M, Grohmann KK, Hernández-Sacristán C, Laska A-C, & Varlokosta S on behalf of the Collaboration of Aphasia Trialists (2014).

Time for a step change? Improving the efficiency, relevance, reliability, validity and transparency of aphasia rehabilitation research through core outcome measures, a common data set and improved reporting criteria. **Aphasiology** 28(11): 1385–1392.

#### Abstract

Considered and meticulous outcome measurement is central to rigorously conducted effectiveness trials, and in turn the relevance and reliability of the study findings to the patient, therapist or policy maker. Failure to include valid and reliable outcome measurements is ethically questionable and wastes already limited research resources. Well-chosen outcome measures ensure that the impact of the research findings extends beyond the conclusions of the specific study. Outcome measures should not only capture clinically meaningful or functionally relevant change in stroke survivors but should also facilitate comparison to other clinical trials, clinical populations, inform meta-analyses and other synthesis approaches.

This paper highlights the need for greater co-ordination and harmonisation of international aphasia researchers' perspectives in order to achieve an agreement on core outcome measures, a common data set and high-quality reporting. It describes the the Collaboration of Aphasia Trialists and our aims in this regard.

#### 2. Isaksen, J [DK], Jensen, LR [DK]. (2015)

CATs - et netværk af afasiforskere. Logos, 73, 19.

#### Abstract (translated from Danish)

Madeline Cruice, speech and language therapist and researcher in aphasia at City University in London, visited Denmark in January 2014 supported by a travel grant from the Collaboration of Aphasia Trialists (CATs). The purpose of her visit was to host a workshop for Danish therapists and collect data for a research project about speech and language therapy knowledge and quality of life within the rehabilitation of aphasia. This article is about the workshop and research project (a manuscript reporting the first phase of results has been written up separately and submitted to a journal). **3.** Aguiar V, Bastiaanse R, Capasso R, Gandolfi M, Smania N, Rossi G, Miceli G. (2015).

Can tDCS enhance item-specific effects and generalization after linguistically motivated aphasia therapy for verbs? Frontiers in Behavioral Neuroscience, 9, 190.

#### Abstract

*Background:* Aphasia therapy focusing on abstract properties of language promotes both item-specific effects and generalization to untreated materials. Neuromodulation with transcranial Direct Current Stimulation (tDCS) has been shown to enhance itemspecific improvement, but its potential to enhance generalization has not been systematically investigated. Here, we test the efficacy of ACTION (a linguistically motivated protocol) and tDCS in producing item-specific and generalized improvement in aphasia.

*Method*: Nine individuals with post-stroke aphasia participated in this study. Participants were pre-tested with a diagnostic language battery and a cognitive screening. Experimental tasks were administered over multiple baselines. Production of infinitives, of finite verbs and of full sentences were assessed before and after each treatment phase. Nonword repetition was used as a control measure. Each subject was treated in two phases. Ten daily 1-h treatment sessions were provided per phase, in a double-blind, cross-over design. Linguistically-motivated language therapy focusing on verb inflection and sentence construction was provided in both phases. Each session began with 20 min of real or sham tDCS. Stimulation site was determined individually, based on MRI scans.

*Results:* Group data showed improved production of treated and untreated verbs, attesting the efficacy of behavioral treatment, and its potential to yield generalization. Each individual showed significant item-specific improvement. Generalization occurred in the first phase of treatment for all subjects, and in the second phase for two subjects. Stimulation effects at the group level were significant for treated and untreated verbs altogether, but a ceiling effect for Sham cannot be excluded, as scores between real tDCS and Sham differed only before treatment.

*Conclusion:* Our data demonstrate the efficacy of ACTION and suggest that tDCS may enhance both item-specific effects and generalization.

#### 4. Zakariás L, Keresztes A, Marton K, & Wartenburger I. (2016)

Positive Effects of a Computerized Working Memory and Executive Function Training on Sentence Comprehension in Aphasia. Neuropsychological Rehabilitation. 1-18.

#### Abstract

Aphasia, the language disorder following brain damage, is frequently accompanied by deficits of working memory and executive functions. Recent studies suggest that WM, together with certain executive functions, can play a role in sentence comprehension in individuals with aphasia, and that working memory can be enhanced with intensive practice. Our aim was to investigate whether a combined working memory and executive functions training improves the understanding of spoken sentences in IWA. We used a pre-post-test case control design. Three individuals with chronic aphasia practised an adaptive training task (a modified *n*-back task) three to four times a week for a month. Their performance was assessed before and after the training on outcome measures related to working memory and spoken sentence comprehension. One participant showed significant improvement on the training task, another showed a tendency for improvement, and both of them improved significantly in spoken sentence comprehension. The third participant did not improve on the training task, however, she showed improvement on one measure of spoken sentence comprehension. Compared to controls, two individuals improved at least in one condition of the WM outcome measures. Thus, our results suggest that a combined working memory and executive functions training can be beneficial for individuals with aphasia.

#### 5. Wallace, SJ [AU], Worrall, L [AU], Rose, T [AU], Le Dorze, G. [CA] (2016).

Core Outcomes in Aphasia Treatment Research? An e-Delphi Consensus Study of International Aphasia Researchers. American Journal of Speech Language Pathology, 25(4S), S729-S742. doi:10.1044/2016\_AJSLP-15-

0150 http://ajslp.pubs.asha.org/article.aspx?articleid=2594841

#### Abstract

*Purpose* The purpose of this article is to identify outcome constructs that aphasia researchers consider essential to measure in all aphasia treatment research.

*Method* Purposively sampled researchers were invited to participate in a 3-round e-Delphi exercise. In Round 1, an open-ended question was used to elicit important outcome constructs; responses were analyzed using inductive content analysis. In Rounds 2 and 3, participants rated the importance of each outcome using a 9-point rating scale. Outcomes reaching predefined consensus criteria were further analyzed using International Classification of Functioning, Disability and Health coding.

Results Eighty researchers commenced Round 1, with 72 completing the entire survey. High response rates ( $\geq$  85%) were achieved in subsequent rounds. Consensus was reached on 6 outcomes: (a) language functioning in modalities relevant to study aims, (b) impact of treatment from the perspective of the person with aphasia (PWA), (c) communication-related quality of life, (d) satisfaction with intervention from the perspective of the PWA, (e) satisfaction with ability to communicate from the perspective of the PWA, and (f) satisfaction with participation in activities from the perspective of the PWA.

*Conclusions* Consensus was reached that it is essential to measure language function and specific patient-reported outcomes in all aphasia treatment research. These results will contribute to the development of a core outcome set.

#### 6. Cruice M, Isaksen J, Randrup-Jensen L, Eggers Viberg M, ten Kate O. (2016)

Practitioners' perspectives on quality of life in aphasia rehabilitation in Denmark. Folia Phoniatrica et Logopaedica 67:131-144

#### Abstract

*Objective:* This study reports on Danish speech and language therapists' knowledge and understanding of quality of life (QOL) in aphasia, including therapists' views on education and training in relation to preparedness for working on QOL, use of measures, and barriers to applying QOL in practice.

*Methods:* 14 Danish clinicians completed a 48-item online questionnaire regarding their views, perspectives and practices that included multiple-choice questions, rating scales, and boxes permitting free text responses. Descriptive statistics were used to characterize the numerical data, and content analysis was applied to text responses.

*Results:* The clinicians interpreted QOL as subjective wellbeing and participation, and explored it with most clients and relatives using informal methods, primarily conversation, for the purposes of identifying relevant goals to direct treatment. Clinicians perceived a need for greater theoretical, practical and experiential knowledge regarding QOL. They also identified a need for translated QOL instruments and training in these measures in practice.

*Conclusion:* Despite a reported lack of knowledge about and tools for measuring QOL, Danish clinicians are applying QOL issues in their practice and perceive these issues as valuable and important in assessment and therapy. The findings have clear implications for tool development, and workforce education.

7. Worrall L, Brady MC, Simmons-Mackie N, Wallace S, Rose T, Murray LL, Hallowell B. (2016)

### Let's call it "aphasia": Rationales for eliminating the term "dysphasia". International Journal of Stroke 11(8) 848-851.

#### Abstract

Health professionals, researchers, and policy makers often consider the two terms aphasia and dysphasia to be synonymous. The aim of this paper is to argue the merits of the exclusive use of the term aphasia and present a strategy for creating change through institutions such as the WHO-ICD. Our contention is the one term avoids confusion, speech-language pathologists prefer aphasia, scholarly publications indicate a preference for the term aphasia, stroke clinical guidelines indicate a preference for the term aphasia, consumer organizations use the title aphasia in their name and on their websites, and languages other than English use a term similar to aphasia. The use of the term dysphasia in the broader medical community may stem from the two terms being used interchangeably in the ICD10. Aphasia United http://www.shrs.uq.edu.au/aphasiaunited, an international movement for uniting the voice of all stakeholders in aphasia within an international context, will seek to eliminate the use of the term dysphasia

#### 8. Rofes A, de Aguiar V, Miceli G. (2015)

#### A minimal standardization setting for language mapping tests: an Italian example. Neurol Sci 36: 1113.

#### Abstract

During awake surgery, picture-naming tests are administered to identify brain structures related to language function (language mapping), and to avoid iatrogenic damage. Before and after surgery, naming tests and other neuropsychological procedures aim at charting naming abilities, and at detecting which items the subject can respond to correctly. To achieve this goal, sufficiently large samples of normed and standardized stimuli must be available for preoperative and postoperative testing, and to prepare intraoperative tasks, the latter only including items named flawlessly preoperatively. To discuss design, norming and presentation of stimuli, and to describe the minimal standardization setting used to develop two sets of Italian stimuli, one for object naming and one for verb naming, respectively. The setting includes a naming study (to obtain picture-name agreement ratings), two on-line questionnaires (to acquire age-of-acquisition and imageability ratings for all test items), and the norming of other relevant language variables. The two sets of stimuli have >80 % picture-name agreement, high levels of internal consistency and reliability for imageability and age of acquisition ratings. They are normed for psycholinguistic variables known to affect lexical access and retrieval, and are validated in a clinical population. This framework can be used to increase the probability of reliably detecting language impairments before and after surgery, to prepare intraoperative tests based on sufficient knowledge of pre-surgical language abilities in each patient, and to decrease the probability of false positives during surgery. Examples of data usage are provided. Normative data can be found in the supplementary materials.

#### 9. Campbell P, Visch-Brink E, Pollock A, Brady MC. (submitted)

#### Post-stroke aphasia and peripheral hearing loss: a systematic review. Neurology

#### Abstract

*Objective:* Aphasia, a language disorder affecting speaking, understanding, reading and writing, is experienced by a third of stroke survivors. As the incidence of stroke increases with age, a significant proportion of survivors will also have age-related hearing problems, which may compound the communication impairment and impede rehabilitation efforts. We aim to systematically review and synthesise the available evidence relating to peripheral hearing loss amongst people with stroke-related aphasia.

*Methods:* We systematically searched the Cochrane Stroke Group Trials Register, CENTRAL, AMED, MEDLINE, EMBASE, CINAHL (from inception to 20 November 2016). We hand-searched reference lists and contacted experts. We included all studies that documented peripheral hearing in people with stroke-related aphasia, using pure tone audiometry as the core index test. Two reviewers independently applied selection criteria and extracted information related to measurement and prevalence of hearing loss, aphasia and hearing aid use. Methodological quality was assessed using CASP checklists. Data was tabulated and summarised in a narrative format.

*Results:* We identified 8618 titles and screened 705 abstracts for eligibility. Thirteen studies met our inclusion criteria. Studies were subject to multiple methodological biases limiting direct comparison between studies. Reported prevalence of hearing loss amongst people with aphasia ranged from 19-93% (n=488). Three studies reported the use of amplification in people with stroke-related aphasia. Based on these data, hearing loss that may have benefited from hearing aid amplification would have remained undetected and uncorrected in 50% - 90% participants.

*Conclusion:* Hearing loss is common in people with aphasia, however it remained undetected and untreated. There is insufficient high quality evidence relating to the prevalence and impact of hearing loss amongst individuals with aphasia following a stroke.

10. Fyndanis V, Lind M, Varlokosta S, Kambanaros M, Soroli E, Grohmann K, Ceder K, Rofes A, Simonsen HG, Bjekić J, Gavarró A, Kuvač Kraljević J, Martínez-Ferreiro S, Munarriz A, Pourquié M, Vuksanović J, Zakariás L, Howard D. (2017).

Cross-linguistic adaptations of The Comprehensive Aphasia Test: Challenges and solutions. Clinical linguistics & phonetics.

#### Abstract

Comparative research on aphasia and aphasia rehabilitation is challenged by the lack of comparable assessment tools across different languages. In English, a large array of tools is available, while in most other languages, the selection is more limited. Importantly, assessment tools are often simple translations and do not take into consideration specific linguistic and psycholinguistic parameters of the target languages. As a first step in meeting the needs for comparable assessment tools, the Comprehensive Aphasia Test is currently being adapted into a number of languages spoken in Europe. In this article, some key challenges encountered in the adaptation process and the solutions to ensure that the resulting assessment tools are linguistically and culturally equivalent, are proposed. Specifically, we focus on challenges and solutions related to the use of imageability, frequency, word length, spelling-to-sound regularity and sentence length and complexity as underlying properties in the selection of the testing material. 11. Rofes A, Zakariás L, Ceder K, Lind M, Blom Johansson M, De Aguiar V, Bjekić J., Fyndanis V, Gavarró A, Gram Simonsen H, Hernández Sacristán C, Kambanaros M, Kuvač Kraljević J, Martínez-Ferreiro S, Mavis I, Méndez Orellana C, Salmons I, Sör I, Lukács A, Tunçer M, Vuksanovic J, Munarriz Ibarrola A, Pourquie M, Varlokosta S, Howard D (in press). '

### Imageability ratings across languages'. Behavioral research methods. DOI: 10.3758/s13428-017-0936-0

#### Abstract

Imageability is a psycholinguistic variable that indicates how well a word gives rise to a mental image or sensory experience. Imageability ratings are used extensively in psycholinguistic, neuropsychological, and aphasiological studies. However, little formal knowledge exists about whether and how these ratings are associated between and within languages. Fifteen imageability databases were cross-correlated using nonparametric statistics. Some of these corresponded to unpublished data collected within a European research network—the Collaboration of Aphasia Trialists (COST IS1208). All but four of the correlations were significant. The average strength of the correlations (rho = .68) and the variance explained ( $R^2$  = 46%) were moderate. This implies that factors other than imageability may explain 54% of the results. Imageability ratings often correlate across languages. Different possibly interacting factors may explain the moderate strength and variance explained in the correlations: (1) linguistic and cultural factors; (2) intrinsic differences between the databases; (3) range effects; (4) small numbers of words in each database, equivalent words, and participants; and (5) mean age of the participants. The results suggest that imageability ratings may be used cross-linguistically. However, further understanding of the factors explaining the variance in the correlations will be needed before research and practical recommendations can be made.

12. Wallace SJ, Worrall L, Rose T, Le Dorze G, Cruice M, Isaksen J, Pak Hin Kong A, Simmons-Mackie N, Scarinci N, Christine Alary Gauvreau (2016).

### Which Outcomes are Most Important to People with Aphasia and Their Families? An International Nominal Group Technique Study. Disability and Rehabilitation, 1-16.

#### Abstract

*Purpose:* To identify important treatment outcomes from the perspective of people with aphasia and their families using the ICF as a frame of reference.

*Methods:* The nominal group technique was used with people with aphasia and their family members in seven countries to identify and rank important treatment outcomes from aphasia rehabilitation. People with aphasia identified outcomes for themselves; and family members identified outcomes for themselves and for the person with aphasia. Outcomes were analysed using qualitative content analysis and ICF linking.

*Results:* A total of 39 people with aphasia and 29 family members participated in one of 16 nominal groups. Inductive qualitative content analysis revealed the following six themes: (1) Improved communication; (2) Increased life participation; (3) Changed attitudes through increased awareness and education about aphasia; (4) Recovered normality; (5) Improved physical and emotional well-being; and (6) Improved health (and support) services. Prioritized outcomes for both participant groups linked to all ICF components; primary activity/participation (39%) and body functions (36%) for people with aphasia, and activity/participation (49%) and environmental factors (28%) for family members. Outcomes prioritized by family members relating to the person with aphasia, primarily linked to body functions (60%).

Conclusions: People with aphasia and their families identified treatment outcomes which span all components of the ICF. This has implications for research outcome measurement and clinical service provision which currently focuses on the measurement of body function outcomes. The wide range of desired outcomes generated by both people with aphasia and their family members, highlights the importance of collaborative goal setting within a family-centred approach to rehabilitation. These results will be combined with other stakeholder perspectives to establish a core outcome set for aphasia treatment research. Implications for Rehabilitation Important outcomes for people with aphasia and their families span all components of the ICF. The relevancy and translation of research findings may be increased by measuring and reporting research outcomes which are important to people living with aphasia. The results of this study indicate that important treatment outcomes for people living with aphasia most frequently link to the activity/participation and body function components of the ICF. The outcomes identified in this study suggest 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 with clients and their families.

#### 13. Wallace, SJ [AU], Worrall, L [AU], Rose, T [AU], Le Dorze, G [CA] (2016).

Which treatment outcomes are most important to aphasia clinicians and managers?

#### An international e-Delphi consensus study. Aphasiology, 1-31.

#### Abstract

*Background* Clinicians have expressed frustration at the lack of strong evidence for aphasia treatments. Inconsistent outcome measurement practices across treatment trials have negatively impacted the quality and strength of evidence for aphasia interventions. Core outcome sets (COSs; minimum sets of outcomes/outcome measures) are increasingly being used to maximise the quality, relevancy, transparency, and efficiency of health treatment research. The current study is the third in a trilogy of stakeholder perspectives to inform the development of a COS for aphasia treatment research.

*Aims* To identify essential aphasia treatment outcomes from the perspective of an international sample of clinicians and managers working in aphasia rehabilitation.

Methods & Procedures A three-round e-Delphi exercise was conducted with aphasia clinicians and managers. In total, 265 clinicians and 53 managers (n = 318) from 25 countries participated in round 1. In round 1, participants responded to the open-ended question, "In your opinion, what are the most important outcomes (results) from aphasia treatment?" Responses were analysed using inductive content analysis. In rounds 2 and 3, 153 and 137 participants respectively rated the importance of each outcome generated in round 1 using a nine-point rating scale. Outcomes reaching predefined consensus criteria were further analysed using the International Classification of Functioning Disability and Health (ICF) coding.

*Outcomes & Results* Analysis of round 1 participant responses produced 1709 codes, which were condensed into 90 subcategories, 25 categories, and 4 themes. In rounds 2 and 3, a total of 51 outcomes reached consensus. The two outcomes with the highest levels of consensus both related to communication between the person with aphasia and their family/carers/significant others. Outcomes relating to people with aphasia most frequently linked to the ICF activity/participation component (52%), whilst outcomes relating to family/carers/significant others were evenly divided between the ICF activity/participation component (36%) and environmental factors (36%).

*Conclusions* Consensus was reached on 51 essential aphasia treatment outcomes. Very high levels of consensus (97–99%) between clinicians were achieved for outcomes relating to communication between the person with aphasia and their communication partner/s, suggesting that in the clinical environment improved dyadic communicative interaction is an important indicator of treatment success. The high proportion of outcomes linking to the ICF activity/participation component highlights the importance of measuring outcomes beyond impairment, both in clinical and research settings. These findings will be combined with other stakeholder perspectives and a systematic review of outcome measures to develop a COS for aphasia treatment research.

#### 14. Brady MC [UK], Kelly H [UK], Godwin J [UK], Enderby P [UK], Campbell P [UK]. Speech and language therapy for aphasia following stroke. Cochrane Database of Systematic Reviews 2016, Issue 6. Art. No.: CD000425

#### Abstract

*Background* Aphasia is an acquired language impairment following brain damage that affects some or all language modalities: expression and understanding of speech, reading, and writing. Approximately one third of people who have a stroke experience aphasia.

*Objectives* To assess the effects of speech and language therapy (SLT) for aphasia following stroke.

Search methods We searched the Cochrane Stroke Group Trials Register (last searched 9 September 2015), CENTRAL (2015, Issue 5) and other Cochrane Library Databases (CDSR, DARE, HTA, to 22 September 2015), MEDLINE (1946 to September 2015), EMBASE (1980 to September 2015), CINAHL (1982 to September 2015), AMED (1985 to September 2015), LLBA (1973 to September 2015), and SpeechBITE (2008 to September 2015). We also searched major trials registers for ongoing trials including ClinicalTrials.gov (to 21 September 2015), the Stroke Trials Registry (to 21 September 2015), Current Controlled Trials (to 22 September 2015), and WHO ICTRP (to 22 September 2015). In an effort to identify further published, unpublished, and ongoing trials we also handsearched the International Journal of Language and Communication Disorders (1969 to 2005) and reference lists of relevant articles, and we contacted academic institutions and other researchers. There were no language restrictions.

Selection criteria Randomised controlled trials (RCTs) comparing SLT (a formal intervention that aims to improve language and communication abilities, activity and participation) versus no SLT; social support or stimulation (an intervention that provides social support and communication stimulation but does not include targeted therapeutic interventions); or another SLT intervention (differing in duration, intensity, frequency, intervention methodology or theoretical approach).

*Data collection and analysis* We independently extracted the data and assessed the quality of included trials. We sought missing data from investigators.

*Results* We included 57 RCTs (74 randomised comparisons) involving 3002 participants in this review (some appearing in more than one comparison). Twenty-seven randomised comparisons (1620 participants) assessed SLT versus no SLT; SLT resulted in clinically and statistically significant benefits to patients' functional communication (standardised mean difference (SMD) 0.28, 95% confidence interval (CI) 0.06 to 0.49, P = 0.01), reading, writing, and expressive language, but (based on smaller numbers) benefits were not evident at follow-up. Nine randomised comparisons (447 participants) assessed SLT with social support and stimulation; meta-analyses found no evidence of a difference in functional communication, but more participants withdrew from social support interventions than SLT. Thirty-eight randomised comparisons (1242 participants) assessed two approaches to SLT. Functional communication was significantly better in people with aphasia that received therapy at a lower intensity, lower dose, or over a shorter period of time. The benefits of a high intensity or a high dose of SLT were confounded by a significantly higher dropout rate in these intervention groups. Generally, trials randomised small numbers of participants across a range of characteristics (age, time since stroke, and severity profiles), interventions, and outcomes.

15. Wallace SJ [AU], Worrall L [AU], Rose T [AU], Le Dorze G [CA], Cruice M [UK], Isaksen J [DK], Pak Hin Kong A [US], Simmons-Mackie N [US], Scarinci N [AU], Christine Alary Gauvreau [CA] (2016).

Which Outcomes are Most Important to People with Aphasia and Their Families? An International Nominal Group Technique Study. Disability and Rehabilitation, 1-16.

http://www.tandfonline.com/doi/abs/10.1080/09638288.2016.1194899

#### Abstract

*Purpose:* To identify important treatment outcomes from the perspective of people with aphasia and their families using the ICF as a frame of reference.

*Methods:* The nominal group technique was used with people with aphasia and their family members in seven countries to identify and rank important treatment outcomes from aphasia rehabilitation. People with aphasia identified outcomes for themselves; and family members identified outcomes for themselves and for the person with aphasia. Outcomes were analysed using qualitative content analysis and ICF linking.

*Results:* A total of 39 people with aphasia and 29 family members participated in one of 16 nominal groups. Inductive qualitative content analysis revealed the following six themes: (1) Improved communication; (2) Increased life participation; (3) Changed attitudes through increased awareness and education about aphasia; (4) Recovered normality; (5) Improved physical and emotional well-being; and (6) Improved health (and support) services. Prioritized outcomes for both participant groups linked to all ICF components; primary activity/participation (39%) and body functions (36%) for people with aphasia, and activity/participation (49%) and environmental factors (28%) for family members. Outcomes prioritized by family members relating to the person with aphasia, primarily linked to body functions (60%).

*Conclusions:* People with aphasia and their families identified treatment outcomes which span all components of the ICF. This has implications for research outcome measurement and clinical service provision which currently focuses on the measurement of body function outcomes. The wide range of desired outcomes generated by both people with aphasia and their family members, highlights the importance of collaborative goal setting within a family-centred approach to rehabilitation. These results will be combined with other stakeholder perspectives to establish a core outcome set for aphasia treatment research.

# 16. Franklin, S [IE], Harhen, D [IE], Hayes, M [IE], Mc Manus, S [IE] and Pollock, A [UK].

Top 10 research priorities relating to long-term aphasia following stroke; what do we know and what do we need to know? Aphasiology.

DOI: 10.1080/02687038.2017.1417539

*Background*: Pollock et al. (2014, Top 10 research priorities relating to life after stroke – Consensus from stroke survivors, caregivers, and health professionals, *International Journal of Stroke*, *9*, 313–320) applied the James Lind Alliance methodology to derive the top 10 priorities for research relating to life after stroke. Many of the initial Treatment Uncertainties related to aphasia.

Aim: The current study uses these Treatment Uncertainties to derive the shared top 10 research priorities of people with aphasia (PWA), their carers and speech and language therapists (SLTs)

*Methods & Procedures:* Treatment Uncertainties relating to aphasia were identified from the 226 unique unanswered questions relating to life after stroke generated by Pollock et al. Using these 34 Treatment Uncertainties relating to aphasia, the last two stages of the JLA method (survey followed by consensus meeting) were carried out with PWA, their carers and SLTs. Participants ranked the top 10 priorities from the 34 given in the survey. Communication ramps were used with the PWA. The 16 highest ranked uncertainties were presented at the consensus meeting, where the final shared top 10 priorities were agreed, merging some statements and refining the wording in others.

*Outcomes & Results*: Participants included PWA with severely affected communication. The methodology produced consensus on a range of priorities including the best treatments and most effective service delivery, management of psychosocial issues, helping volunteers and carers, and research into treating severe forms of aphasia.

*Conclusions:* PWA are able to participate fully in research priority setting. These shared research priorities represent an excellent base for the development of clinically important research in aphasia, addressing issues which are of greatest importance to key stakeholders.

## 17. Hege Prag Øra [NO], Melanie Kirmess [NO], Marian Brady [UK], Ingvild Winsnes [NO], Frank Becker [NO].

Aphasia telerehabilitation post stroke- Protocol of a randomized controlled trial.

(submitted)

18. The RELEASE Collaborators (LR Williams (UK), K VandenBerg (UK), M Ali (UK), A Elders (UK), J Godwin (UK), S Abel (UK), M Abo (JP), C Brandenburg (AU), T Cranfill (US), M di Pietro- Bachmann (CH), J Fillingham (UK), F Galli (IT), B Glize (FR), P Jaecks (DE), B Jefferies (UK), E Khedr (EG), E Kyoung Kang (KR), A Kong (US), MA Lambon Ralph (UK), M Laganaro (CH), B Leeman (CH), A Leff (UK), RR Lima (BR), A Lorenz (DE), B MacWhinney (US), IP Martins (PT), F Mattioli (IT), , M Meinzer (AU), R Nilipour (IR), E Noé Sebastián (ES), N-J Paik (KR),, I Papathanasiou (GR), T Prizl Jakovac (HR), E Rochon (CA), C Rosso (FR), I Rubi- Fesson (DE), M Ruiter (NL), R Shisler Marshall (US), S Small (US), C Snell (UK), JP Szaflarski (US), H Wright Harris (US), MC Brady (UK).

Development of a collaborative international aphasia research database for the REhabilitation and recovery of peopLE with Aphasia after StrokE ('RELEASE') project.

Paper in preparation.

19. Vuksanovic J [RS], Zivanovic M [RS], Laska AC [SE], Filipovic S [RS].

Predictors and prognosis for people with aphasia following stroke.

Paper in preparation.

20. Cruice M [UK], Randrup-Jensen L [DK], ten Kate O [DK], Eggers Viberg M [DK], Isaksen J [DK] Impact of a brief educational intervention and implementation period on practitioners' perspectives and practice in aphasia rehabilitation in Denmark.

Paper in preparation

21. Horton S [UK], Soskolne V [IL], Olenik D [IL], Isaksen J [DK], Jagoe C [IE], Shiggins C [UK], Pearl G [UK], Haaland-Johansen L [NO], McMenamin R [IR].

Asset-based approaches to living with aphasia: case studies exploring the relevance and implications for people with aphasia and families.

Paper in preparation

# **11. Conferences**

#### **11.1 Platform Presentations**

**1.** Brady MC on behalf of the Collaboration of Aphasia Trialists. Fostering a collaborative international aphasia research network.

Platform presentation at British Aphasiology Society Biennial International Conference, Manchester. September 2013.

http://www.britishaphasiologysociety.org.uk/conferences

2. Campbell P, Visch-Brink E, Pollock A, Brady M. Post-stroke aphasia and peripheral hearing loss: A systematic review of prevalence, audiological assessment and hearing aid use.

Platform presentation at RCSLT 'Mind the Gap" conference, Leeds, UK. 2014

http://www.rcslt.org/news/events/past\_events\_docs/rcslt\_conference\_2014\_presentations /po werpoint\_versions

**3.** Brady MC on behalf of the Collaboration of Aphasia Trialists. Aphasia Research: Trials and tribulations, cooperation and collaborations. 2014

Platform presentation at International Aphasia Rehabilitation Conference, The Hague, Netherlands. 18th-20th June 2014

http://iarc2014.com/page/Programme

**4.** Zakariás L, Keresztes A, & Marton K (2014). Positive effects of computerized executive function training in aphasia. Stem-, Spraak- en Taalpathologie 19 (Suppl.), 178–181.

Platform presentation at Proceeding of the Science of Aphasia Conference 2014

http://www.sstp.nl/

- 5. Campbell P. Screening for hearing loss in the first 30 days after stroke. (Invited speaker).
- Conference presentation as a result of STSM at Stroke Best Practice Event. Greater Glasgow and Clyde NHS, Glasgow UK. 4 March 2015

http://www.nhsggc.org.uk/

- 6. Campbell P. The eye is not a lonely miracle hearing loss after stroke.
- Conference presentation as a result of STSM at Vision after Stroke Conference (Multidisciplinary stroke researcher conference), SSVHN, Perth, Scotland, UK. 27 October 2014.

No link

- **7.** Campbell P. Post-stroke aphasia and peripheral hearing loss: A systematic review of prevalence, audiological assessment and hearing aid use.
- Platform presentation as a result of STSM at 'Mind the Gap', Royal College Speech and Language Therapists Conference (multidisciplinary conference). Leeds, UK. 17 September 2014.

https://www.rcslt.org/news/events/2014/rcslt\_conference\_2014

- **8.** Campbell P. The commonwealth of the Senses hearing loss after stroke. Symposium 1: Evidence based stroke care update.
- Platform presentation as a result of STSM at the Scottish Stroke Allied Health Professions Forum Conference (multidisciplinary stroke researcher conference), Perth, Scotland, UK. 12 June 2014.
- https://www.chss.org.uk/health-professionals/professional-forums-groups/scottish-strokeahp- forum-ssahpf/
- **9.** Campbell P, Visch-Brink E, Pollock A, Brady M. Aphasia after stroke and peripheral hearing loss: A systematic review of prevalence, audiological assessment and hearing aid use. Clinical Rehabilitation 2015; 29(4): 399-400

Platform presentation at the Society of Research in Rehabilitation (SRR), UK

http://journals.sagepub.com/doi/full/10.1177/0269215515570099

- **10.** Seçkin Arslan, Eren Gür & Claudia Felser: Which factors predict agrammatic comprehension of Wh-questions in Turkish and German individuals with aphasia?
- Platform presentation as a result of CATs network at 5th Novi Sad Workshop on Psycholinguistic, Neurolinguistic and Clinical Linguistic Research

http://digitalna.ff.uns.ac.rs/sadrzaj/2017/978-86-6065-417-7

- **11.** Silvia Martínez Ferreiro, Byurakn Ishkhanyan, Kasper Boye: Prepositions in Spanish-speaking individuals with aphasia: Evidence from connected discourse.
- Platform presentation as a result of CATs network at 5th Novi Sad Workshop on Psycholinguistic, Neurolinguistic and Clinical Linguistic Research

http://digitalna.ff.uns.ac.rs/sadrzaj/2017/978-86-6065-417-7

**12.** Jasmina Vuksanović, Tanja Milovanović, Ljubica Konstantinović & Saša R. Filipović: Effect of language therapy on receptive language recovery in patients with acute aphasia.

Platform presentation as a result of CATs network at 5th Novi Sad Workshop on Psycholinguistic, Neurolinguistic and Clinical Linguistic Research

http://digitalna.ff.uns.ac.rs/sadrzaj/2017/978-86-6065-417-7

 Fyndanis, V [EL], Lind, M [NO], Varlokosta, S [EL], Gram Simonsen, H [NO], Kambanaros, M [CY], Ceder, K SE], Rofes, A [IE], Soroli, E [FR], Bjekic, J [RS], Gavarró, A [ES], Grohmann, K [CY], Kuvac, J [RS], Martinez Ferreiro, S [NL], Munarriz, A [ES], Vuksanovic, [RS], Zakarias, LHU] & Howard, D [UK] (2016)

Crosslinguistic adaptations of The Comprehensive Aphasia Test: challenges and solutions.'

- Conference presentation at 16th ICPLA (International Clinical Phonetics and Linguistics Association) Conference, Halifax, Canada. 2016.
- https://www.dal.ca/content/dam/dalhousie/pdf/sites/icpla/2016%20ICPLA%20Conference %20 Programme.pdf
- **14.** The RELEASE Collaboration [WG3, WG4] 'RELEASE: Rehabilitation and recovery of people with aphasia after stroke'
- Platform presentation at Collaboration of Aphasia Trialists (CATs) Annual Conference, University of Tampere, Finland. 2016

http://www.aphasiatrials.org

#### 15. The RELEASE Collaboration [WG3, WG4]

The RELEASE Collaboration - LR Williams (UK), K VandenBerg (UK), M Ali (UK), A Elders (UK), J Godwin (UK), S Abel (UK), M Abo (JP), F Becker (NO), A Bowen (UK), C Brandenburg (AU), C Breitenstein (DE), D Copland (AU), T Cranfill (US), ES Duncan (US), M di Pietro-Bachmann (CH), J Fillingham (UK), M Gandolfi (IT), B Glize (FR), E Godecke (AU), K Hilari (UK), J Hinckley (US), S Horton (UK), D Howard (UK), P Jaecks (DE), B Jefferies (UK), LMT Jesus (PT), M Jungblut, (DE), M Kambanaros, (CY), E Khedr (EG), T Kukkonen (FI), E Kyoung Kang (KR), MA Lambon Ralph (UK), M Laganaro (CH), A-C Laska (SE), B Leeman (CH), A Leff (UK), RR Lima (BR), A Lorenz (DE), B MacWhinney (US), IP Martins (PT), F Mattioli (IT), İ Maviş (TR), M Meinzer (AU), E Noé Sebastián (ES), R Nilipour (IR), N-J Paik (KR), R Palmer (UK), B Patricio (PT), C Price (UK), T Prizl Jakovic (PT), E Rochon (CA), M Rose (AU), C Rosso (FR), I Rubi-Fesson (DE), M Ruiter (NL), R Shisler Marshall (US), C Snell (UK), JP Szaflarski (US), S Thomas (UK), I van de Meulen (NL), M van de Sandt-Koenderman(NL), E Visch-Brink (NL), L Worrall (AU), H Wright Harris (US), MC Brady (UK)

'Establishing an international shared aphasia individual patient dataset for the REhabilitation and recovery of peopLE with Aphasia after StrokE (RELEASE) project'

Platform presentation at the International Aphasia Rehabilitation Conference (IARC), City, University of London, UK. 14/12/16

#### http://www.city.ac.uk/iarc-2016

- **16.** Karianne Berg, Sarah Wallace, Caitlin Brandenburg, Claire Penn, Madeline Cruice & Linda Worrall [WG5]. Establishing a consensus on an updated definition of aphasia.
- Platform presentation as a result of a STSM at the 17th International Aphasia Rehabilitation Conference, London. 14-16 December, 2016

#### http://www.city.ac.uk/iarc-2016

- **17.** L Zakariás [HU, DE], A Keresztes [HU, DE], K Marton [USA]. Positive effects of computerized cognitive training on sentence comprehension in aphasia.
- Presentation at Learning and Plasticity Meeting, Akaslompolo, Finland, April 13-15, 2015 (cross-disciplinary meeting connecting psychological and neuroscience research)
- http://www.utu.fi/en/units/tbmc/files/events/conferences/Pages/Learning-and-Plasticity-2015.aspx
- **18.** Wallace, SJ [AU], Worrall, L [AU], Rose, T [AU], Le Dorze, G [CA]. Core Outcomes in Aphasia: An e-Delphi Consensus Study of International Aphasia Clinicians and Managers.
- Conference presentation at Postgraduate Research Conference, University of Queensland, Brisbane, Australia. November 2015.

**19.** Wallace, SJ [AU], Worrall, L [AU], Rose, T [AU], Le Dorze, G [CA]. Core Outcomes in Aphasia Treatment Research? An e-Delphi Consensus Study of International Aphasia Researchers.

Conference presentation at Clinical Aphasiology Conference, Monterey, USA. May 2015.

- C Breitenstein [DE], T Grewe[DE], A Flöel3[DE], W Ziegler DE], P Martus [DE], L Springer [DE], Huber[DE], Willmes[DE], S Abel [UK], Glindemann [DE], Domahs [DE] Regenbrecht[DE], Schlenck [DE], Thomas [DE], de Langen [DE], A Baumgartner[UK]. Standardisierung der deutschsprachigen Version der "Stroke and Aphasia Quality of Life Scale 39 / SAQOL-39 [the German adaptation of the SAQOL-39]
- The Annual Meeting of the German Society for Aphasia Research and Treatment(GAB)in November 2015 in Innsbruck, Austria.
- Report of the processes and procedures of the German adaptation of the SAQOL-39. Manuscript in preparation.
- http://www.aphasiegesellschaft.de/files/8914/3974/9636/Vorlaeufiges\_Programm\_GAB\_In nsb ruck\_2015\_14082015.pdf
- **20.** Kuvac Kraljevic, Jelena [HR], Kovacevic, Melita [HR], Hrzica, Gordana [HR], Olujic, Marina [HR] Matic, Ana [HR], Lice , Karolina [HR]

Challenges in the adaptation of CAT Test: Croatian experience.

Conference presentation at 30th World Congress of the International Association of Logopedics and Phoniatrics (IALP). Dublin, Ireland. 21-25 August 2016.

http://ialpdublin2016.org/

**21.** Franklin, S [IE], Harhen, D [IE], Hayes, M [IE], Mc Manus, S [IE], Pollock, A [UK] (2015).

Top 10 research priorities relating to long-term aphasia

British Aphasiology Society Biennial International Conference 2015, University College London, UK

http://www.bas.org.uk/BASocWeb/wp-content/uploads/2015/11/BAS-2015-prog-at-aglance-1Sept-BW.pdf 22. The RELEASE Collaboration - LR Williams (UK), K VandenBerg (UK), M Ali (UK), A Elders (UK), J Godwin (UK), S Abel (UK), M Abo (JP), F Becker (NO), A Bowen (UK), C Brandenburg (AU), C Breitenstein (DE), D Copland (AU), T Cranfill (US), ES Duncan (US), M di Pietro-Bachmann (CH), J Fillingham (UK), M Gandolfi (IT), B Glize (FR), E Godecke (AU), K Hilari (UK), J Hinckley (US), S Horton (UK), D Howard (UK), P Jaecks (DE), B Jefferies (UK), LMT Jesus (PT), M Jungblut, (DE), M Kambanaros, (CY), E Khedr (EG), T Kukkonen (FI), E Kyoung Kang (KR), MA Lambon Ralph (UK), M Laganaro (CH), A-C Laska (SE), B Leeman (CH), A Leff (UK), RR Lima (BR), A Lorenz (DE), B MacWhinney (US), IP Martins (PT), F Mattioli (IT), İ Maviş (TR), M Meinzer (AU), E Noé Sebastián (ES), R Nilipour (IR), N-J Paik (KR), R Palmer (UK), B Patricio (PT), C Price (UK), T Prizl Jakovic (PT), E Rochon (CA), M Rose (AU), C Rosso (FR), I Rubi-Fesson (DE), M Ruiter (NL), R Shisler Marshall (US), C Snell (UK), JP Szaflarski (US), S Thomas (UK), I van de Meulen (NL), M van de Sandt-Koenderman(NL), E Visch-Brink (NL), L Worrall (AU), H Wright Harris (US), MC Brady (UK).

RELEASE: Creating an international, multidisciplinary, individual patient database.

European Forum for Rehabilitation Research and the Society for Rehabilitation Research, Glasgow May 2017.

http://www.efrr2017.com/

## **11.2 Conference Posters**

23. Isaksen, J.K., Jensen, L.R. & Cruice, M. (2015). Danske logopæders perspektiv påg anvendelse af livskvalitet i afasirehabiliteringen. Logos, no. 73

Poster presentation at the 5th Nordic Aphasia Conference, Oslo, Norway. 11-13 June 2015

http://www.nac2015.no/

24. Isaksen, J [DK], Jensen, L [DK], Cruice, M [UK], ten Kate, O [DK], & Eggers Viberg, M [DK] (2015). Practitioners' perspectives on quality of life in aphasia rehabilitation in Denmark.

Poster presentation at the 5th Nordic Aphasia Conference, Oslo, Norway. 11-13 June 2015.

http://inss.ku.dk/english/calendar/nordic-aphasia-conference 2017/NAC\_2017\_Programme\_\_updated\_160517.pdf

25. Rehabilitation and recovery of people with aphasia after stroke: the RELEASE project. Poster Gandolfi M, Smania N, Williams LR, Ali M, Vandenberg K, Godwin J, Elders A, Brady MC

Poster presentation at XVI Congresso Nazionale SIRN

http://www.sirn.net/IT/eventi.xhtml/id/281-xvi-congresso-nazionale-sirn

26. Rofes, A., Zakariás, L., Ceder, K., Lind, M., Bloom Johansson, M., Bjekić, J., Fyndanis, V., Gavarró, A., Simonsen, H. G., Hernández-Sacristán, C., Kuvač Kraljević, J., Martínez-Ferreiro, S., Mavis, I., Méndez Orellana, C., Meteyard, L., Salmons, I., Sör, I., Tunçer, M., Vuksanovic, J., Varlokosta, S., & Howard, D.

Word imageability from a cross- linguistic perspective. Stem-, Spraak- en Taalpathologie, 21, 158-161.

**27.** The RELEASE Collaboration [WG3, WG4] 'RELEASE: Rehabilitation and recovery of people with aphasia after stroke'

Poster presentation at National Congress of the Italian Society of Neurological Rehabilitation (SIRN). 7-9/04/2016

- http://www.sirn.net/IT/index.xhtml
- **28.** The RELEASE Collaboration [WG3, WG4] 'RELEASE: Rehabilitation and recovery of people with aphasia after stroke'

Poster presentation at Life After Stroke Day, Glasgow Caledonian University, UK (Multidisciplinary event for stroke researchers, clinicians and general public) 20/05/16

http://www.aphasiatrials.org/index.php/meetings-events/other-associated-activities/life-after- stroke-open-day-20th-may

**29.** The RELEASE Collaboration [WG3, WG4] 'Building on the past: Systematic identification, data extraction and synthesis of pre-existing individual stroke patient datasets to inform the development and design of future clinical trials'

Poster presentation at the International Clinical Trials Methodology Conference. 08-10/04/17

http://www.ictmc2017.com/

**30.** Hege Prag Øra, Melanie Kirmess, Marian Brady, Ingvild Winsnes, Frank Becker: "Aphasia telerehabilitation post stroke- Protocol of a randomized controlled trial"

Poster Presentation as a result of a STSM at the CATS Conference, Erasmus University Medical Center, The Netherlands. 2016

#### http://www.aphasiatrials.org/images/Abstract\_book.pdf

**31.** Ingvild Winsnes , Hege Prag Øra, Melanie Kirmess, Frank Becker : "Aphasia telerehabilitation – A digital enterprise"

Poster presentation as a result of STSM at the 6<sup>th</sup> Nordic Aphasia Conference in Copenhagen 15-17 June 2017

http://inss.ku.dk/english/calendar/nordic-aphasia-conference-2017/franklin

32. The RELEASE Collaboration - Ali M (UK), Becker F (NO), Brady MC (UK), Bowen A (UK), Elders A (UK), Godecke E (AU), Godwin J (UK), Hilari K (UK), Hinckley J (US), Horton S (UK), Howard D (UK), Jesus LMT(PT), Kagan A (CA), Kukkonen T(FI), Laska AC (SE), MacWhinney B (US), van der Meulen I(NL), Palmer R (UK), Price C (UK), Thomas S (UK), Visch-Brink EG (NL), VandenBerg K (UK), Williams LR (UK), Worrall L (AU).

RELEASE: Rehabilitation and recovery of people with aphasia after stroke.

National Congress of the Italian Society of Neurological Rehabilitation (SIRN), April 2016.

- 33. The RELEASE Collaboration Williams LR [UK], Ali M [UK], Vandenberg K UK, , Godwin J [UK], Elders A [UK], Abel, S [UK], Abo M [JP], Becker F [NO], Bowen A [UK], Brandenburg C [AU], Breitenstein C [DE], David Copland [AU], Cranfill T [US]; Duncan ES [US], di Pietro-Bachmann M [CH], Fillingham J [UK], Galli F [IT], Gandolfi M [IT], Glize B [FR], Godecke E [AU], Hilari K [UK], Hinckley J [US], Horton S [UK], Howard D [UK], Jaecks P [DE], Jefferies B [UK], Jesus L [PT], Jungblut M [DE], Kyoung Kang E [KR], Kambanaros M [CY], Khedr E [EG], Kukkonen T [FI], Lambon Ralph M [UK], Laganaro M [CH], Laska A-C [SE], Law SP [CN], Leeman B [CH], Leff A [UK], Ribeiro Lima R [BR], Lorenz A [DE], MacWhinney B [US], Mattioli F [IT], Mavis I [TR], Meinzer M, [AU], Noé Sebastián E [ES], Nilipour R [IR], Paik NJ [KR], Palmer R [UK], Papathanasiou I [EL], Patricio B [PT], Shisler Marshall R [US], Pavão Martins I, [PT], Prizl Jakovac T [HR], Price C [UK], Rochon E [CA], Rose M [AU], Rosso C [FR], Rubi-Fessen I, [DE], Ruiter M, [NL], Snel C [UK], Szaflarski JP [US], Thomas S [UK], van der Meulen I [NL], van de Sandt-Koenderman M [NL], Visch-Brink E [NL], Wright Harris H [US], Worrall L [AU], Brady MC [UK].
- Creating an international, multidisciplinary aphasia dataset of individual patient data for the REhabilitation and recovery of peopLE with Aphasia after StrokE (RELEASE) project.

UK Stroke Forum, Liverpool, UK, December 2016

- 34. The RELEASE Collaboration Elders A [UK], Ali M [UK], Vandenberg K UK, Williams LR [UK], Godwin J [UK], Abel, S [UK], Abo M [JP], Becker F [NO], Bowen A [UK], Brandenburg C [AU], Breitenstein C [DE], David Copland [AU], Cranfill T [US]; Duncan ES [US], di Pietro-Bachmann M [CH], Fillingham J [UK], Galli F [IT], Gandolfi M [IT], Glize B [FR], Godecke E [AU], Hilari K [UK], Hinckley J [US], Horton S [UK], Howard D [UK], Jaecks P [DE], Jefferies B [UK], Jesus L [PT], Jungblut M [DE], Kyoung Kang E [KR], Kambanaros M [CY], Khedr E [EG], Kukkonen T [FI], Lambon Ralph M [UK], Laganaro M [CH], Laska A-C [SE], Law SP [CN], Leeman B [CH], Leff A [UK], Ribeiro Lima R [BR], Lorenz A [DE], MacWhinney B [US], Mattioli F [IT], Mavis I [TR], Meinzer M, [AU], Noé Sebastián E [ES], Nilipour R [IR], Paik NJ [KR], Palmer R [UK], Papathanasiou I [EL], Patricio B [PT], Shisler Marshall R [US], Pavão Martins I, [PT], Prizl Jakovac T [HR], Price C [UK], Rochon E [CA], Rose M [AU], Rosso C [FR], Rubi-Fessen I, [DE], Ruiter M, [NL], Snel C [UK], Szaflarski JP [US], Thomas S [UK], van der Meulen I [NL], van de Sandt-Koenderman M [NL], Visch-Brink E [NL], Wright Harris H [US], Worrall L [AU], Brady MC [UK].
- Building on the past: Systematic identification, data extraction and synthesis of pre-existing individual stroke patient datasets to inform the development and design of future clinical trials.

International Clinical Trials Methodology Conference, Liverpool, UK April 2017.

http://www.ictmc2017.com/programme/

35. Franklin, S [IE], Harhen, D[IE], Hayes, M[IE], Mc Manus, S [IE], Pollock, A [UK] (2016).

Top 10 research priorities relating to long-term aphasia following stroke'

SPHeRE 2nd Annual Conference Population health and health services research in Ireland: current trends and future directions Dublin, Ireland.

http://www.sphereprogramme.ie/secondconference

**36.** Shiggins C [UK], Soskolne V [IL], Olenik D [IL], Pearl G [UK], Haaland-Johansen L, Isaksen J [DK], Jagoe C [IE], McMenamin R [IE], Horton S [UK].

Towards asset-based approaches to promoting and sustaining well-being for people with aphasia and their families.

Irish Association of Speech and Language Therapy (IASLT) conference. Dublin. May 25th & 26th, 2017.

http://conference.iaslt.ie/

### **11.3 Collaboration Conferences**

### **2014**

1. Management Committee and Working Group Meetings, 5-6th May, 2014 Hosted in Nice, France by Dr Charlotte Jacquemot of the Ecole Normale Supérieure, Paris.

2. Management Committee and Working Group Meetings, 5-6th May, 2014 Hosted in Dublin, Ireland by Professor Sue Franklin of the University of Limerick.

# 2015

3. Multi-disciplinary workshops co-hosted with Science of Aphasia Conference Hosted in Aveiro, Portugal by Dr Luis Jesus of the University of Aveiro, Portugal

 Management Committee and Working Group Meetings, 30th September – 1st October 2015

Hosted by Dr Maria Kambanaros of the Technological University of Cyprus, Cyprus

## 2016

5. Management Committee and Working Group Meetings, 11-13th February 2016 Hosted by Tarja Kukkonen of the University of Tampere, Finland

6. Management Committee and Working Group Meetings, 5-7th March 2015 Hosted by Dr Madeline Cruice at City, University of London, UK

## 2017

7. Management Committee and Working Group Meetings, 6-8th February 2017 Hosted by Dr Mieke van de Sandt-Koenderman, Rijndam Rehabilitation Center & Erasmus University Rotterdam, The Netherlands

### **Presentations at Action Conferences**

1. The RELEASE Collaboration [WG3, WG4] 'Creating an international shared aphasia individual patient dataset for the REhabilitation and recovery of peopLE with Aphasia after StrokE (RELEASE) project'

Platform presentation at the Collaboration of Trialists (CATs), Erasmus University Medical Center, Rotterdam, Netherlands. 08/02/17

http://www.aphasiatrials.org/index.php/meetings-events/cats-conference-2017

 Becker F [NO] et al. Aphasia telerehabilitation early post stroke – design of a randomized controlled trial at the Collaboration of Aphasia Trialists Conference London March , 2015.

http://www.aphasiatrials.org/index.php/meetings-events/cats-conference-2015/catsconference-programme

- 3. Leijten M[BE], Drijbooms E [NL], Behrns I [SE] Cognitive writing process characteristics of aphasia patients: A case study.
- http://www.aphasiatrials.org/index.php/meetings-events/cats-conference-2015/catsconference-programme
- 4. Franklin, S [IE], Harhen, D., Hayes, M., Mc Manus, S and Pollock, A [UK]. Top 10 research priorities relating to long-term aphasia following stroke consensus from people with aphasia, caregivers and health professionals

Collaboration of Aphasia Trialists Conference March 2015, London, UK.

http://www.aphasiatrials.org/index.php/meetings-events/cats-conference-2015/catsconference-programme

- 5. Prag Øra H [NO], Kirmess M [NO], Brady M [UK], Winsnes I [NO], Becker F [NO] Aphasia telerehabilitation post stroke- protocol of a randomized controlled trial
- Collaboration of Aphasia Trialists Conference, Erasmus University Medical Center Rotterdam February 2017

http://www.aphasiatrials.org/index.php/meetings-events/cats-conference-2017

 Horton, S [UK], Pearl, G [UK], Soskolne, V [UK], Olenik, D [UK], Haaland-Johansen, L [NO], Isaksen, J [DK], Jagoe, C [IE] & Shiggins, C [UK] Asset-based approaches for stroke survivors with aphasia and their families: promoting and sustaining well-being in the long-term.

Collaboration of Aphasia Trialists conference. Rotterdam. February 2017

http://www.aphasiatrials.org/index.php/meetings-events/cats-conference-2017

 Wallace, SJ [AU], Worrall, L [AU], Rose, T [AU], Le Dorze, G [CA] and Cruice, M [UK] Results of an International Consensus Meeting to Develop a Core Outcome Set for Aphasia Treatment Research. Collaboration of Aphasia Trialists (CATs) Conference, Rotterdam, The Netherlands, February 2017.

http://www.aphasiatrials.org/index.php/meetings-events/cats-conference-2017

 Ali M [UK], Lifshitz Ben Basat [IL], A, Berthier M [ES], Breitenstein C [DE], Constantinidou [CY], Cruice M [UK], Davila G, Elders A [UK], Gandolfi M-L [IT], Gil M [IL], Godecke
 E [AU], Jesus LMT [PT], Martinez Jiminez L, Kambanaros M [CY], Kukkonen T [FI], Laska
 A-C [SE], Mavis I [TR], McMenamin R [IE], Obrig H [DE], Ostberg P, Robson H [UK], Sage
 K [UK], van de Sandt-Koenderman M [NL], Visch-Brink EG [NL], Wielaert S [NL], Wallace
 S [AU], Brady MC [UK]. International Practice-Based Rehabilitation approaches to Aphasla after StrokE (IPRAISE)

Collaboration of Aphasia Trialists Conference, February 2017, Rotterdam, The Netherlands.

http://www.aphasiatrials.org/images/Program\_final\_COST\_conference.pdf

- M Ali [UK], A Lifshitz Ben Basat [IL], M Berthier [ES], C Breitenstein [DE], F Constantinidou [CY], M Cruice [UK], G Davila [IL], A Elders [UK], M-L Gandolfi [IT], M Gil [IL], E Godecke [AU], LMT Jesus [PT], L Martinez Jiminez, M Kambanaros [CY], T Kukkonen [FI], A-C Laska [SE], I Mavis [TR], R McMenamin [IE], H Obrig [DE], P Ostberg, H Robson [UK], K Sage [UK], M van de Sandt-Koenderman [NL], EG Visch-Brink [NL], S Wielaert [NL], S Wallace [AU] and MC Brady [AU].
- Development of standardised outcomes for use in an international, observational poststroke aphasia study (International Practice-Based Rehabilitation approaches to Aphasia after StrokE).

Collaboration of Aphasia Trialists Conference, February 2017, Rotterdam, The Netherlands.

http://www.aphasiatrials.org/images/Program\_final\_COST\_conference.pdf

- The RELEASE Collaboration LR Williams (UK), K VandenBerg (UK), M Ali (UK), A Elders (UK), J Godwin (UK), S Abel (UK), M Abo (JP), F Becker (NO), A Bowen (UK), C Brandenburg (AU), C Breitenstein (DE), D Copland (AU), T Cranfill (US), ES Duncan (US), M di Pietro-Bachmann (CH), J Fillingham (UK), M Gandolfi (IT), B Glize (FR), E Godecke (AU), K Hilari (UK), J Hinckley (US), S Horton (UK), D Howard (UK), P Jaecks (DE), B Jefferies (UK), LMT Jesus (PT), M Jungblut, (DE), M Kambanaros, (CY), E Khedr (EG), T Kukkonen (FI), E Kyoung Kang (KR), MA Lambon Ralph (UK), M Laganaro (CH), A-C Laska (SE), B Leeman (CH), A Leff (UK), RR Lima (BR), A Lorenz (DE), B MacWhinney (US), IP Martins (PT), F Mattioli (IT), İ Maviş (TR), M Meinzer (AU), E Noé Sebastián (ES), R Nilipour (IR), N-J Paik (KR), R Palmer (UK), B Patricio (PT), C Price (UK), T Prizl Jakovic (PT), E Rochon (CA), M Rose (AU), C Rosso (FR), I Rubi-Fesson (DE), M Ruiter (NL), R Shisler Marshall (US), C Snell (UK), JP Szaflarski (US), S Thomas (UK), I van de Meulen (NL), M van de Sandt-Koenderman(NL), E Visch-Brink (NL), L Worrall (AU), H Wright Harris (US), MC Brady (UK)
- REhabilitation and recovery of peopLE with Aphasia after StrokE (RELEASE): The creation of a multidisciplinary, international aphasia database of individual patient data.

Collaboration of Aphasia Trialists Conference, February 2017, Rotterdam, The Netherlands.

http://www.aphasiatrials.org/images/Program\_final\_COST\_conference.pdf

 Fyndanis, V [EL], Lind, M [NO], Varlokosta, S [EL], Gram Simonsen, H [NO], Kambanaros, M [CY], Ceder, K SE], Rofes, A [IE], Soroli, E [FR], Bjekic, J [RS], Gavarró, A [ES], Grohmann, K [CY], Kuvac, J [RS], Martinez Ferreiro, S [NL], Munarriz, A [ES], Vuksanovic, [RS], Zakarias, LHU] & Howard, D [UK]. Cross-linguistic adaptations of The Comprehensive Aphasia Test.

Collaboration of Aphasia Trialists Conference, February 2017, Rotterdam, The Netherlands.

http://www.aphasiatrials.org/images/Program\_final\_COST\_conference.pdf

12. Pourquie M [ES], Munarriz A [ES] Basque adaptation of the Comprehensive Aphasia Test.

Collaboration of Aphasia Trialists Conference, February 2017, Rotterdam, The Netherlands.

http://www.aphasiatrials.org/images/Program\_final\_COST\_conference.pdf

13. Visch-Brink [e NL], Kukkonen T [FI], Knoph M [NO], Gil M [IL], Best W [UK], Denes F [IT], Rose M [AU], Nouwens F [NL], van de Sandt-Koenderman M [NL], Dipper L [UK], Kornev A [RU], Brady MC [UK]. Aphasia Intervention descriPtion In Research (AsPIRE)

Collaboration of Aphasia Trialists Conference, February 2017, Rotterdam, The Netherlands.

http://www.aphasiatrials.org/images/Program final COST conference.pdf

14. Franklin S [IE] Visch-Brink E [NL], van de Sandt-Koenderman M [NL], Nouwens F [NL], Mendez C [CL]

Collaboration of Aphasia Trialists Conference, February 2017, Rotterdam, The Netherlands.

http://www.aphasiatrials.org/images/Program final COST conference.pdf

15. Berg K [NO], Worrall L [UK]. Establishing a consensus on an updated definition of aphasia. Collaboration of Aphasia Trialists Conference, February 2017, Rotterdam, The Netherlands.

http://www.aphasiatrials.org/images/Program final COST conference.pdf

16. Wallace, SJ [AU], Worrall, L [AU], Rose, T [AU], Le Dorze, G [CA], Cruice, M [UK], Simmons-Mackie, N [CA], Isaksen, J [DK], Kong, A [USA], Scarinci, N [AU]. Which Outcomes are Most Important to People Living with Aphasia? An International Nominal Group Technique Study. Clinical Aphasiology Conference 2015, May Monterey, USA

https://www.regonline.com/Register/Checkin.aspx?EventId=1582105

# 12. Other outputs / achievements

Reflecting our ambitions to impact on the future of aphasia research and rehabilitation some of our Collaboration outputs did not fall neatly into traditional academic outputs such as peer reviewed publications, conference presentations or workshop. These some of these additional outputs, particularly those considered highly impactful, are listed here.

#### Information materials for people with aphasia (in Zulu)

#### Caitlin Longman [ZA], Claire Penn [ZA]

'What is aphasia?' http://www.aphasiatrials.org/images/Aphasia Zulu Booklet Spreads 2.pdf

'Communication cards' http://www.aphasiatrials.org/images/Aphasia Sawubona Card 1.pdf

'Emergency Information about aphasia cards' http://www.aphasiatrials.org/images/Aphasia Hello Card 2.pdf

**International Consensus Meeting** to establish a Core Outcome Set for Aphasia Research (December 2016) London, U.K.

Attendees; Ann-Charlotte Laska [SE], Arpita Bose [UK], David Copland [AU], Deborah Hersh [AU], Elizabeth Rochon [CA], Karen Sage [UK], Katerina Hilari [UK], Jane Marshall [UK], Janet Patterson [US], Janet Webster [UK], Helen Kelly [IE], Leora Cherney [US], Marian Brady [UK], Madeline Cruice [UK], Marjorie Nicholas [US], Miranda Rose [AU], Pamela Enderby [UK], Steven Small [US], Swathi Kiran [UK], Tami Howe [NZ and CA] and Caterina Breitenstein [DE].

#### Consensus was reached for:

Language: The Western Aphasia Battery Revised (WAB-R) (74% consensus) Psychological well-being: General Health Questionnaire (GHQ)-12 (83% consensus) Quality of Life: Stroke and Aphasia Quality of Life Scale (SAQOL-39) (96% consensus) Communication: consensus was not achieved that reached the pre-defined consensus criteria of 70% for inclusion in the COS and will be sought at a later date. Participation: there was consensus that a measure of participation should be included in the core outcome set but in the absence of suitable measurement tools a decision on a particular outcome measure should be sought at a later date. The next meeting is planned to take place alongside the International Aphasia Rehabilitation Conference in Portugal 2018.

#### Round Table at the

17th International Aphasia Rehabilitation Conference (IARC), 2016, December, London, UK.

Wallace, SJ [AU], Worrall, L [AU], Rose, T [AU], Le Dorze, G [CA]. Implementing a Core Outcome Set for Aphasia Treatment Research: Barriers, Facilitators and the Development of an Action Plan.

#### http://www.city.ac.uk/iarc-2016/programme

#### **Guidelines and Consensus Statements (UK)**

Our Cochrane Review contributed to the UK Royal College of Physicians' National Clinical Guidelines on Stroke (2016)

#### **Guidelines and Consensus Statements (NO)**

Our Cochrane Review contributed to the development of the Norwegian Clinical Guidelines on stroke (In preparation)

#### **Guidelines and Consensus Statements (SE)**

Our Cochrane Review contributed to the development of the Swedish Clinical Guidelines on stroke (In preparation)

# **13. Social Media**

"There is a real need to enhancing therapists' access to materials on aphasia for a range of languages. The CATs network started a good web information about that, still ongoing." COST Action Rapporteur 2017

### 13.1 CATs on Twitter

Social Media: Regular updates on activities and outputs via Twitter feed @CATs\_Aphasia

#### https://twitter.com/cats aphasia

International, multidisciplinary audience researchers (clinical linguists, speech and language therapists, psychologists, neurologists), people with aphasia, students and therapists.

875 followers across target audience groups; 714 Tweets; 163 Twitter Likes



Fig. 9 CATs Twitter profile

### **13.2 CATS on Facebook**

Social Media: Regular updates on activities and outputs via Facebook feed @ CATs.aphasia

#### https://www.facebook.com/CATs.aphasia/

Our Final Action Conference (2017) was streamed live on our Facebook page. We guest curated the World Stroke Organisation (WHO) and the International Journal of Stroke's Twitter accounts during our two-day Conference.

Facebook has provided important examples of successful dissemination activities which directly targeted members of the public thus raising the awareness of aphasia amongst the public.

To bank their side of Collaboration of Aphasia Trialists @CATs.aphasia	If Lked* Following* Recommend	Send Message
Home About Photos Videos	Status  Photo/Video	Medical and health
	Cotor Write something on this Page	Community See all
Posts	Photos	264 people follow this
Community Create a Page		About         See All           O         Send message           Image: See All statistical and peath         Image: See All statistical and peath           Image: Madeut and health         Image: See All statistical and peath
		People Also Like

Fig. 9 CATs Facebook profile

# 14. Media Coverage

#### Media Coverage:

Following the Writing Workshop, Dr Celia Woolf's press release reporting the findings of her randomised controlled trial had significant impact

Woolf C, Caute A, Haigh Z, Galliers J, Wilson S, Kessie A, et al. A comparison of remote therapy, face to face therapy and an attention control intervention for people with aphasia: a quasi-randomised controlled feasibility study. Clinical Rehabilitation 2016;30(4):359-73. (http://openaccess.city.ac.uk/8288/)

Arise TV live interview (Arise TV is an international news channel on cable/satellite) <u>http://www.city.ac.uk/news/2015/june/skype-therapy-helps-those-lost-for-words-after-a-stroke</u>.

Published article 'Funziona la terapia su Skype per chi ha perso la parola dopo un ictus' (27/05/2015)

ADN Kronos (General readership in Italian: 2.136.000 unique visitors per month) http://www.adnkronos.com/salute/medicina/2015/05/27/funziona-terapia-skype-per-chi-perso- parola-dopoictus\_FKPXXqDs9I3U4370Ca0uFO.html

All news 24 http://www.allnews24.eu/funziona-la-terapia-su-skype-per-chi-ha-perso-la-parola-dopo-un- ictus/

Arezzo Web http://www.arezzoweb.it/2015/funziona-la-terapia-su-skype-per-chi-ha-perso-la-parola-dopo- un-ictus-305882.html

Eco Seven http://www.ecoseven.net/adnkronos/lavoro-e-salute/funziona-la-terapia-su-skype-per-chi-ha- perso-laparola-dopo-un-ictus

Focus http://www.focus.it/scienza/salute/funziona-la-terapia-su-skype-per-chi-ha-perso-la-parola- dopo-un-ictus

// Farmacista
http://www.ilfarmacistaonline.it/scienza-efarmaci/articolo.php?articolo\_id=28548&cat\_1=5&cat\_2=0&tipo=articolo

Giornale http://www.giornaledellumbria.it/article/article228235.html

Media Coverage: Published article 'Funziona la terapia su Skype per chi ha perso la parola dopo un ictus' (27/05/2015) continued

Il meteo

http://www.ilmeteo.it/notizie/italia/funziona-la-terapia-su-skype-per-chi-ha-perso-la-parola- dopo-un-ictus-388855

Intrage

http://www.intrage.it/SaluteEPrevenzione/Pages/Funziona-la-terapia-su-Skype-per-chi-ha- perso-la-parola-dopo-un-ictus.aspx

La Repubblica http://www.repubblica.it/scienze/2015/05/27/news/skype\_ictus-115380986/

La salute in pillole http://www.lasaluteinpillole.it/salute.asp?id=28841

Nonsolofole http://www.nonsolofole.it/?p=322729

Notiziario italiano http://www.notiziarioitaliano.it/La\_video\_chat\_che\_aiuta\_a\_guarire\_Skype\_e\_Facetime\_per\_l a\_terapia\_post\_ictus.8c0dd3276.a.html

Padova News

http://padovanews.it/speciali/salute/356509-funziona-la-terapia-su-skype-per-chi-ha-perso-la-parola-dopoun-ictus.html

Panorama

http://www.panorama.it/scienza/salute/funziona-la-terapia-su-skype-per-chi-ha-perso-la- parola-dopo-unictus-2/

Quotidiano Sanità http://www.quotidianosanita.it/scienza-e-farmaci/articolo.php?articolo\_id=28548"

**RELEASE** project

May 20<sup>th</sup> 2017, Dr Luis Jesus, University of Aveiro

A radio interview with the Portuguese public service broadcaster for radio and television (**Rádio e Televisão de Portugal (RTP) in the progamme** "A arte do possível" (*The art of the possible*) with Filipe Teles . The title of the podcast of that interview is "Projeto RELEASE analisa bases de dados de doentes com afasia; potencialidades da aquacultura multitrófica integrada <u>http://www.rtp.pt/play/p384/e293523/click</u>.

# **15. Impacts**

"The impact is achieved and very important from a scientific point of view." COST Action Rapporteur 2017

# 1. A dynamic collaboration of multidisciplinary aphasia researchers

#### Direct and intended impact

Our active network of multidisciplinary international aphasia researchers included more than <u>170 members from across 26 countries (plus collaborations with researchers from an</u> <u>additional 10 countries)</u>. Within each country MC members created national networks of multidisciplinary aphasia researchers which has proved particularly successful in some countries (e.g. Norway, Sweden). Our 17 Short Term Scientific Missions supported the movement of European researchers <u>involving 15 countries</u> including Cyprus, Greece, Hungary, Germany, Denmark, Netherlands, Russia, Serbia, Sweden, Ireland, South Africa and Australia.

With our follow-on funding support from the Tavistock Trust for Aphasia [UK] for an additional three years of activities (2017-2020) we aim to broaden that reach to become more inclusive of non-COST countries such as the USA, Canada and China.

### 2. An online, sustainable platform to support network activities Direct and intended impact

As a consequence of our Action we developed a sustainable online platform (<u>www.aphasiatrials.org</u>) to support communication amongst our network, facilitating data contribution, data sharing, collaboration, review and dissemination activities. Our Action website was completed and functioned well in its supporting role for our collaboration regardless of an individual researcher's ability to travel to events, access to local resources and networks. We worked to increase our online profile over the course of our Action which has seen more than 17,000 users from a wide range of countries.

# 3. A synergistic programme of aphasia research activities that will enhance the assessment, diagnosis, rehabilitation and recovery of people with aphasia

#### **Direct and intended impact**

Our Action members have developed of a portfolio of 27 collaborative aphasia research activities which benefited from the Action support (see Ongoing activities section of this report and our website http://www.aphasiatrials.org/index.php/research/catsresearch/current-research-projects.) Many of these research projects secured competitive grant awards in excess of €1.1M. An additional 12 funding proposals were also developed some of which are still under review. Activities reflect our 4 research orientated Working Groups' focus on assessments and outcomes, predictors and prognosis, effective interventions and societal impact and reintegration.

# 4. Aphasia research focused on what matters to people with aphasia, their families and healthcare professionals

#### **Direct and intended impact**

We identified the top 10 shared aphasia research priorities from the perspectives of people with aphasia, their families and healthcare professionals [Franklin [IR] and Pollock [UK] (2017). This work will shape our future research activities (much as the Top 10 research priorities for people after stroke has shaped the current stroke rehabilitation research activities -

http://www.thelancet.com/journals/laneur/article/PIIS1474-4422(12)70 029-7/fulltext)

We anticipate that future focus of aphasia research will ensure research activities will become more efficient, more effective and make more of a contribution to societal needs than before the identification of these priorities

### 5. Greater representation of aphasia at policy level

#### Direct and intended impact

Members of the Collaboration of Aphasia Trialists have been invited to contribute their expertise on aphasia research at key national and international policy level.

The draft 2017 update of the <u>Norwegian Stroke Clinical Guidelines</u> are currently out for consultation (as of August 2017).

<u>h</u>ttps://helsedirektoratet.no/horinger/hjerneslag/seksjon?Tittel=rehabili <u>tering-etter-</u> <u>hjerneslag-10734</u>.

Dr Frank Becker led the rehabilitation guideline group which included consideration of the evidence of optimum approaches to the assessment and rehabilitation of aphasia after stroke.

The Fifth Royal College of Physicians National Clinical Guideline for Stroke was published in October 2016. https://www.strokeaudit.org/Guideline/Full-Guideline.aspx Audrey Bowen [UK] was an Editor of these guidelines. The update of the Cochrane review of speech and language therapy for aphasia after stroke (Brady 2016) was conducted to contribute to the development of those guidelines.

# 6. Greater integration of aphasia research and third sector group policy

#### Direct and intended impact

The Stroke Association's [UK Charity] <u>https://www.stroke.org.uk/</u> established an Aphasia Advisory Committee to support charity's policy and decision making in relation to aphasia support and services such as the recently acquired Speakability groups <u>https://www.stroke.org.uk/what-stroke/what-aphasia</u>. Dr Madeline Cruice [UK] and Prof Marian Brady [UK] contribute to this committee alongside other clinical, academic and user expert representatives.

Aphasia Alliance [UK coalition of primarily third sector charity organisations with an interest in supporting people with aphasia http://www.aphasiaalliance.org/] invited UK representation from the Collaboration of Aphasia Trialists within this Alliance to update on aphasia research matters.

#### 7. Increased knowledge of a range of language structures

#### **Direct and intended impact**

In the process of adapting the 14 cross-linguistic CAT tools (Impact 8) the research teams undertook considerable programs of work relating to imageability values for nouns, word frequency calculations and the development of a comprehensive psycholinguistic database of words for each language. This vital new knowledge will impact on the development of future linguistic work (in relation to aphasia and other language and linguistic interests) in these languages in the future.

# 8. Creation of an international, multidisciplinary archive of individual patient data from pre-existing aphasia research records

#### Direct and intended impact

Supported by 18 co-applicants from across 8 countries the Collabortion supported the development of a grant application for the RELEASE (REhabilitation and recovery of peopLE with Aphasia after StrokE) project to develop of a database of pre-existing aphasia research datasets. Funded by the UK National Institute for Health Research (Grant Ref. 14/04/22) the study aims to improve our understanding of the natural history, the predictors of recovery and the components of effective rehabilitation programmes for aphasia through the novel analyses of this database. Beyond the project our ambition is (following relevant permissions and approvals from the contributing primary research teams) to extend access to that database to other aphasia research teams. The RELEASE project is still ongoing and currently involves collaborators from 23 countries. Currently our database includes more than 5,500 individual patient datasets from 174 primary research activities.

#### 9. Improved dissemination of aphasia research

Our Action held two writing workshops and a training school to enhance the quality, efficiency and reach of our efforts to share our aphasia research findings. Prof Chris Code (Editor in Chief of Aphasiology <u>http://www.tandfonline.com/toc/paph20/current</u>) and Prof Nina Simons Mackie considered optimum approaches to the publication of academic articles in journals and writing craft.

We also focused on dissemination of our aphasia research findings beyond the traditional model of academic peer reviewed manuscripts. Working with Prof James C Coyne <u>https://en.wikipedia.org/wiki/James C. Coyne</u> a highly published America Psychologist we considered on-line only open access approaches, the use of Twitter and crafting of press releases and their role in achieving broader impacts with people with aphasia, their families and healthcare professionals.

Our training school and workshops materials continue to be available online to our Action members to further support skills development amongst our group. After drafting a press release within one of our Action writing workshops she was invited to be interviewed live on Arise TV an international news channel on cable/satellite

<u>http://www.city.ac.uk/news/2015/june/skype-therapy-helps-those-lost-</u> <u>for-words-after-a-</u> <u>stroke</u>. The press release was also picked up by several Italian media outlets and a range of on-line sites in France, Italy and the UK for general readerships (see details in other dissemination activities section)

In addition, on the 20th May 2017 Dr Luis Jesus (PT) was invited to participate in a live RTP (Portuguese) radio programme called 'The art of the possible' [ A arte do possível com Filipe Teles] about aphasia and the RELEASE project (Project 3). A podcast of this interview is available

<u>Projeto</u> RELEASE analisa bases de dados de doentes com afasia; potencialidades da aquacultura multitrófica integrada -

http://www.rtp.pt/play/p384/e293523/click

#### 10. Greater access to multilingual aphasia assessment materials

Many non-English speaking language regions lack access to formal aphasia assessment tools in the locally spoken language(s) (e.g. Catalan). The absence of such tools has been a barrier to language assessment which would inform treatment decisions. The development of multilingual adaptations of the Comprehensive Aphasia Test (Swinburn et al 2004 <u>https://www.routledge.com/Comprehensive-Aphasia-Test/Swinburn- Porter-Howard/p/book/9781841693798</u>) across 14 languages (Basque, Catalan, Croatian, Finnish, French, Greek, Hungarian, Lithuanian, Norwegian, Portuguese, Serbian, Spanish, Swedish and Turkish) will be vital to the assessment, diagnosis and rehabilitation of people with aphasia in these regions.

Thoughtful adaptation means that these 14 language adaptations will have the potential to be used internationally – for example the CAT- Spanish adaptation will relevant for use amongst Spanish speakers in Argentina, Uruguay, Colombia, Chile as well as Spain. Shared measurement tools are vital to the progression of multi-national, multilingual shared research activities.

Action members have also adapted other assessment tools into other languages includingThe Token Test in Hebrew Mali Gil [IL]The Boston Naming Test in Maltese (Grima [MT] and Franklin [IR]The Western Aphasia Battery (Revised) in German (Caterina Breitenstein Project25)Scenario Test in German (Caterina Breitenstein Project 25) Stroke and AphasiaQuality of Life (SAQoL-39) in German (Caterina Breitenstein Project 25)Communication Outcome After Stroke (Long, Heskith and Bowen) in Danish(COAST-DK)https://www.click2go.umip.com/i/coa/Carer- COAST-DK.html by LiseRandrup Jensen [DK] Maria Skov Struve Christensen, Lisan KlaabyCarer Communication Outcome After STroke in Danish (C- COAST-DK) by LiseRandrup Jensen [DK] Maria Skov Struve Christensen, Lisan KlaabyCommunication Outcome After STroke in Danish (C- COAST-DK) by LiseRandrup Jensen [DK] Maria Skov Struve Christensen, Lisan KlaabyCommunication Outcome After STroke in Italian (C-COAST-IT) Prof. ValentinaBambini

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# 11. Facilitating great coordination of aphasia research efforts in the future

Following the presentation of the top ten aphasia research priorities (Item 4 above) , the 2016 update of the Cochrane review of Speech and language therapy for aphasia (Brady et al 2016), the publication of several national clinical guideline updates relating to aphasia rehabilitation (Impact 5) we drafted a shared Aphasia Research Agenda for the Collaboration. This research agenda maps the necessary research activities that must be undertaken to enable us to address the important aphasia research priorities. This filtering and mapping exercise considered work that was already ongoing and was linked to the specific interests of the CATs Working Groups and members. This draft research agenda will undergo further consultation with members before being published (Ali et al in preparation). In this way we aim to co-ordinate our shared research activities, increase the efficiency and cost-effectiveness of our future research efforts which will achieve the fastest route to achieve benefits for people with aphasia, their families and healthcare professionals.

# 12. Improved knowledge in the adaptation of outcome measures into multiple languages

The members of Working Group 2 have successfully led the adaptation of assessment tools in a range of languages (Impact 8). In the course of completing this work they have developed an expertise in this challenging and specialist task which may support subsequent language assessment adaptation work in the future (potentially beyond aphasia).

# 13. Shared terminology and understanding of aphasia from multiple disciplinary perspectives

In order to work together it has been vital to consider aphasia from a range of multidisciplinary perspectives and to strive to achieve shared terminology and a shared definition of aphasia. The argument for exclusive use of the term aphasia (rather than outdated term dysphasia) was put forward in the paper 'Let's call it Aphasia' published in the World Stroke Organisation's International Journal of Stroke (Publication 7). It achieved an Altmetric score of 44 meaning it is in the top 5% of all outputs scored by Altmetric. With an Altmetric attention score of 44 it compares well with the mean attention score (3.0) of research outputs from the same journal (n=640).

Current impairment based definitions fail to incorporate the impact of aphasia on an individual's participation and activities. A shared definition could have important consequences for people with aphasia in clinical and research contexts and would strengthen collaborative working across a range of multidisciplinary and research paradigms. Our Action supported a Short Term Scientific Mission to develop a new, shared definition of aphasia which reflected the ICF. Interestingly, despite two surveys of our network membership it was not possible to reach a consensus on terminology. A discussion paper is currently in preparation by Berg [NO] and Worrall [AU] to share some of the findings of this work and which we hope will support the development of a suitable definition of aphasia in the future.

### 14. Multilingual Information on Aphasia

With increased global movement of people and languages worldwide, a single speech and language therapist is likely to encounter people from a wide range of multilingual backgrounds. For example the 2011 UK Census highlighted that in London alone, there are more than 100 languages in daily use.

https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentit y/language/articles/languageinenglandandwales/2013-03-04.

This profile is echoed across other stroke and aphasia services internationally. There is a clear need to enhance therapists' access to materials on aphasia for a range of languages. This was made clear in the recent recommendation from the Royal College of Physicians 2016 stroke clinical guidelines which recommend that where people should be assessed and given information about aphasia in their preferred language.

As highlighted above (Impact 10) our Action addressed the lack of non-English formal assessment tools. We have profiled existing resources on information on aphasia (primarily from <a href="http://www.aphasia-international.com/languages/">http://www.aphasia-international.com/languages/</a>) and funded an STSM by Caitlin Longman to develop an aphasia information resource in isiZulu. These are now available free to access from our website

http://www.aphasiatrials.org/index.php/aphasia-resources/aphasia- support/multilingualinformation-sheets.

#### 15. Consensus on a core outcome set for aphasia research

Amongst the objectives of this Action we sought to develop a core outcome set for aphasia research. Soon after our Action was funded we became aware that a PhD student (Sarah Wallace [AU] now a member of WG5) was working towards a similar goal <a href="http://www.comet-initiative.org/studies/details/287?result=true">http://www.comet-initiative.org/studies/details/287?result=true</a>

Rather than duplicate our efforts our Action supported these activities, circulating surveys across our international network and providing modest support for the consensus meeting in London 2016. We are delighted that considerable progress has been made and a core outcome set has been established and which will support greater synergy amongst future aphasia research activities and data collection. Some further work is required but we believe much will be achieved through a more coordinated approach to outcome measurement across aphasia research.

# **16.** Facilitating rapid dissemination of emerging aphasia research findings across the Collaboration

Across our network we publicize on-going and recently completed randomised controlled trials of interventions for aphasia after stroke. Together with information on newly emerging interventions [Project 3] or the use of tele- rehabilitation for aphasia [Project 5] our network facilitates rapid communication of the latest evidence and new findings across out members. As our members are experts in their field they in turn will be well placed to inform the rehabilitation and recovery of people with aphasia following stroke.

# 16. What next?

"The strategic and coordinated approach to future aphasia research activities is clear in the ten aphasia research priorities. If the CATs network is able to pursue these priorities and respond to each of them over the next two years, the result is of real value."

COST Action Rapporteur 2017

#### CATs2 2017-2020

We are very grateful to the Tavistock Trust for Aphasia (UK) for supporting of a second phase of the Collaboration of Aphasia Trialists (1st of May 2017 until April 2020). During this time we plan to build upon the firm foundations described in this report and address the following objectives

*Objective 1: Continued growth of a multidisciplinary, international network* 

Objective 2: Development of high quality randomised controlled trials of interventions for aphasia

**Objective 3: Development and sharing of trial resources** 

**Objective 4: Capacity Building** 

**Objective 5: Reporting and Dissemination** 

With a new remit to support aphasia research across a range of aetiologies and equal access to membership from any country our next phase of activity promises to be even more productive, ambitious and collaborative.

If you would like to get involved email <u>CATs@gcu.ac.uk</u> If you want to keep up to date with our development visit <u>www.aphasitrials.org</u> or <u>https://twitter.com/CATs\_Aphasia</u>