Creating an international, multidisciplinary, aphasia dataset of individual patient data (IPD) for the REhabilitation and recovery of peopLE with Aphasia after StrokE (RELEASE) project.

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Introduction:
Aphasia affects a third of stroke survivors (~5.6 million worldwide annually). The social and emotional impact of aphasia makes timely and effective rehabilitation vital. Speech and language therapy benefits recovery; however the specific patient, stroke, aphasia and intervention factors which optimise recovery and rehabilitation are unclear. We will explore these uncertainties in our RELEASE study (NIHR HS&DR 14/04/22). In Phase I of this study we aimed to create a large, collaborative, international database of individual patient data (IPD) from pre-existing aphasia research.

Method:
Eligible datasets included IPD of ≥10 people with stroke-related aphasia, with time post-stroke specified and aphasia severity data. Contributions were invited from international, multidisciplinary, aphasia research collaborators via the EU COST funded Collaboration of Aphasia Trialists. We also conducted a systematic search of the literature [Cochrane Stroke Group Trials, MEDLINE, CINAHL, AMED, Cochrane Library Databases (CDSR, DARE, CENTRAL, HTA), EMBASE, LLBA and SpeechBITE from inception to Sept 2015 for additional datasets. Two independent reviewers considered full texts, a third resolved any conflicts.

Results:
As of June 2016 our database included 2,531 IPD from 11 countries (33 datasets). Nine were in the public domain. Following the systematic search of 5,272 records (of which 75 duplicates, 2,395 reference titles and 965 abstracts were excluded) further datasets were identified and the investigators of these datasets invited to collaborate.

Conclusion:
We succeeded in creating a large, collaborative, international aphasia database of pre-existing IPD. A systematic search process to identify additional datasets eligible for inclusion supplemented more informal dataset recruitment methods.

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