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Nursing, Midwifery and Allied Health Professions Research Unit

Support groups for people with aphasia
A national survey of third sector group facilitators in the UK

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Background

National clinical guidelines recommend referring people with aphasia to support groups[1] which provide valuable opportunities for conversation practice, participation in social activities and peer support [2,3]. Groups often provide long-term support after discharge from formal rehabilitation amongst a group of people particularly at risk of social isolation. Alongside patient groups managed by public and private healthcare providers, many communication support groups for people with aphasia are co-ordinated by third sector organisations, ranging from national charities to local voluntary groups. Little is known about the availability, design, delivery, leadership and membership of third sector groups.

Aims

1. To identify the availability, organisational structure, activities and membership of third sector communication support groups across the UK.
2. To gather facilitator ranking of the factors which contribute to the success and sustainability of groups and factors which motivate members to participate.
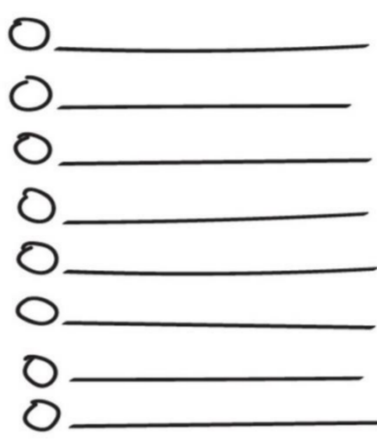
Method

We conducted a national postal survey of third sector support group facilitators.

Population: Facilitators of UK groups who were (a) third sector, (b) community based, and (c) chiefly supporting people with aphasia.

Social Media: We promoted the opportunity to participate in the research to relevant national and local interest groups.

Recipients: We identified facilitators across the UK through individual enquiries, directories provided by national charities, and online searches.

Screening: We spoke to each facilitator to confirm inclusion criteria. We excluded speech and language therapy, health service providers and one-to-one models.
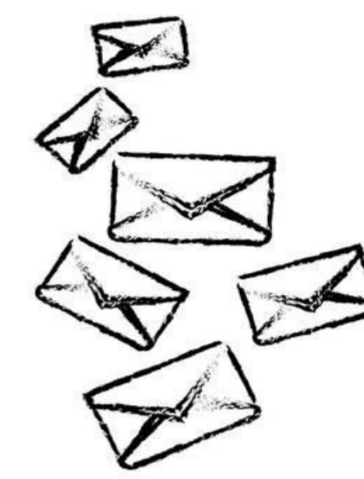
Optimisation: Paper surveys were designed to maximise response rates, piloted and posted to all eligible groups. A reminder was sent two weeks later.
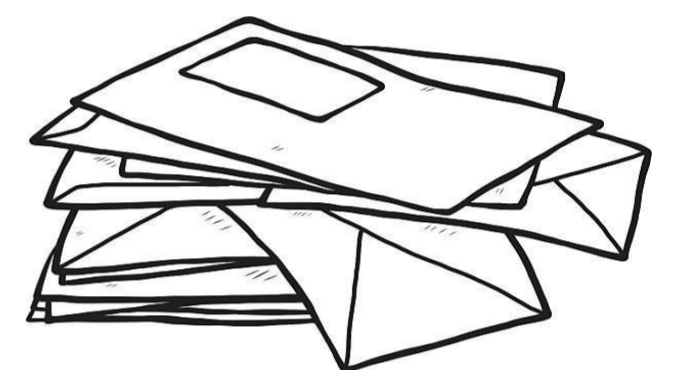
Data: Anonymous data from returned forms were collated and analysed for summary descriptives and facilitator views.

Results

Surveys were distributed to 71 group facilitators representing 99 support groups. Figure 1 describes the eligibility screening process. Distribution maps illustrate the change in apparent availability and accessibility before (*Figure 2*) and after screening (*Figure 3*).

Figure 1: Survey distribution and responses

Figure 2: Before screening

Figure 3: After screening
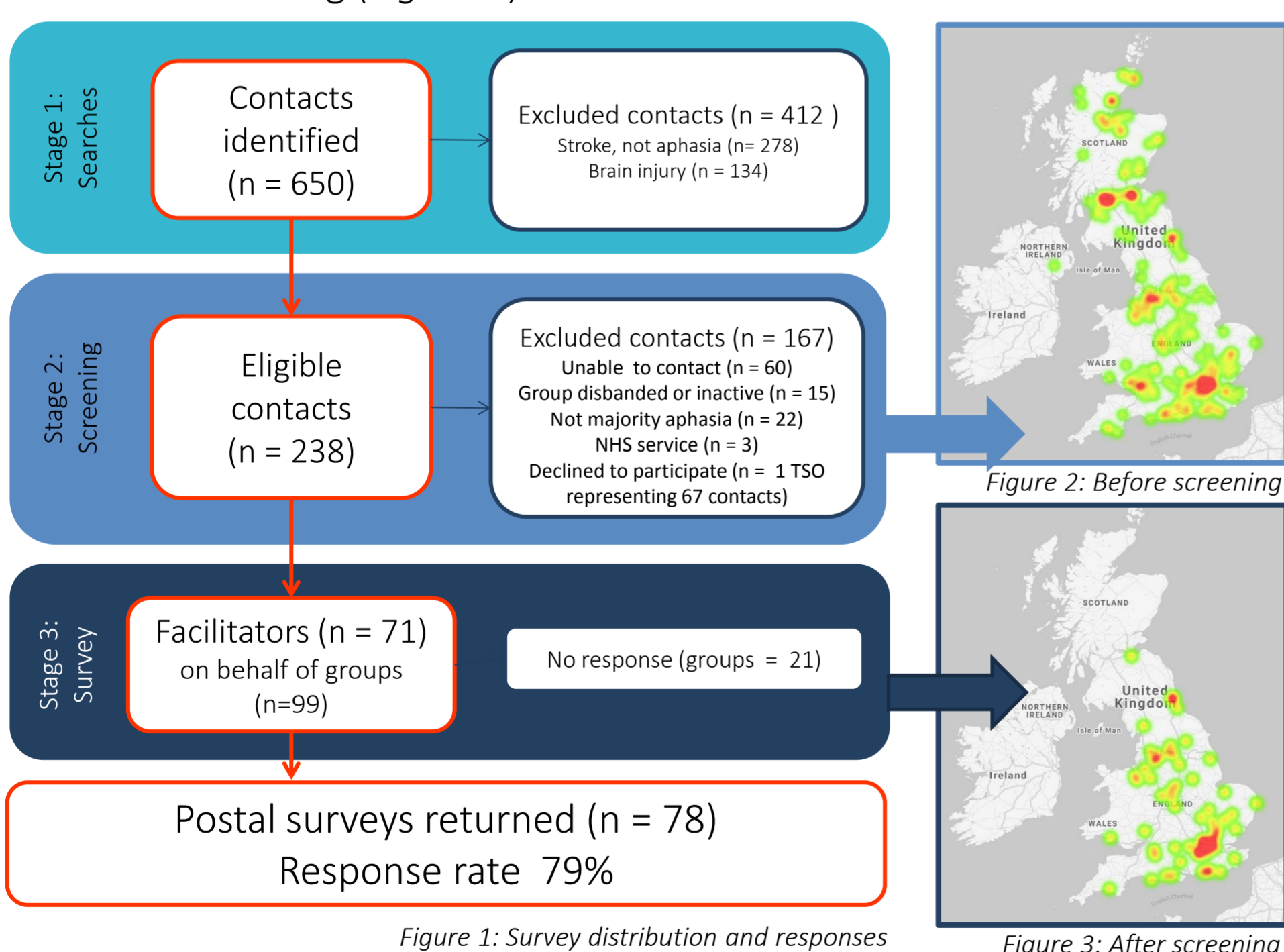
Survey responses for 82 groups (comprising 1768 members) were completed and returned, four responses failed to meet inclusion criteria and were excluded from analysis. The majority of groups (75%) were reported to be part of or affiliated to a national charity.

Table 1: Group characteristics (n=78)	Mean (SD) [range]
Group longevity	12 (11.37) [1-68] years
Group size	19 (11.47) [3-60] members
Duration of membership	8 (6.8) [0-30] years

Survey respondents reported *availability of voluntary help* (23%); *referrals* (16%) and *finding the right focus or activity for the group* (16%) as the top three factors essential to group success.

Factors reported as important to supporting members' attendance were *a warm welcome or induction* (29%); *members' confidence in communicating* (24%); and *positive group dynamics* (23%).

Respondents prioritised communication over support in considering what motivates members to attend, selecting *to get better at communicating* (16%); *to feel confident talking* (13%) and *meeting other people with aphasia* (18%) over *peer support* (10%) or *emotional support* (8%).

Conclusion

Facilitators reported a diverse range of organisational structures and practices, although most groups are affiliated to a larger network. Inequalities were evident in the accessibility of groups nationally. The longevity of groups and their membership is perhaps testament to their valued role but raises questions of sustainability. Facilitators described confident communicating, rather than peer support, as a driver for participation.

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[1] Rudd, A. G., et al. (2016). National clinical guideline for stroke: 5th edition. ClinMed. [2] Attard, M. C., et al. (2015). Aphasiology 29(8): 983-1019. [3] Lanyon, L. E., et al. (2013). IJSLP15(4): 359-374.

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