

# The Implications of Public Awareness and Knowledge of Aphasia around the World

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## Abstract

**Background:** The services provided and the financial support for research into a health condition is influenced by public awareness of a health condition. There has been a wide range of surveys of the public's and health professional's awareness of aphasia throughout the world to gauge levels of awareness. Findings confirm that awareness of aphasia is universally lower than comparable conditions. **Objective:** To provide a review of international public and health workers' awareness and knowledge of aphasia. **Materials and Methods:** A narrative review examining known telephone, internet and face-to-face surveys of aphasia to determine international levels of awareness, knowledge and attempts to raise the awareness of aphasia. **Results:** Awareness is internationally low and actual knowledge is even lower: 1%-66% for awareness and 5%-17% for actual knowledge. While higher than the public, levels of awareness and knowledge are also low among health professionals. A range of demographic variables, like age, sex and socio-economic status, are significantly associated with levels of awareness. People who have some awareness or knowledge of aphasia have gained it from the media or personal and professional contact with aphasia. **Discussion and Conclusion:** Awareness and knowledge of aphasia are low when compared to other communication disorders and comparable neurological conditions, for example, Parkinson's disease. The implications of results for service provision, research funding and awareness-raising programmes are reviewed and further suggestions for awareness-raising are discussed.

**Keywords:** Aphasia, public awareness, public knowledge

**Guest editor's notes:** We are proud to have this invited narrative review from the senior professor of psychology and an aphasiologist at Exeter, UK. The pathetically low public awareness and knowledge about aphasia has dire consequences. One of the foremost goals of advocacy for aphasia by clinicians and other stakeholders like PWA and their caregivers, in India should be to take measures to ameliorate this situation.

## INTRODUCTION

Aphasia affects the use of language, but has a massive impact on everyday life. Lam & Wodchis<sup>[1]</sup> examined health-related quality of life (HRQoL) in 66,193 residents in long-term hospital care using the Health-Status Index (MDS-HSI), universally used in North American long-term care facilities. The analysis examined the impact of 60 diseases and 15 conditions on HRQoL and it was aphasia that showed the largest negative relationship to MDS-HSI, followed by cancer and Alzheimer's disease. A wide range of studies has shown the impact of aphasia on the lives of aphasic people and their families<sup>[2-4]</sup>; despite these striking demonstrations that aphasia has the most extensive negative effects on QoL, awareness of aphasia in the public and healthcare professions is significantly lower than comparable conditions with lower incidence and prevalence than aphasia. This paper reviews the range of studies conducted internationally of the *awareness* (having 'heard of' aphasia) and basic *knowledge* of aphasia and discusses attempts to improve awareness and knowledge.

The frequency of occurrence of a health condition in the media is related to levels of public knowledge of that condition, and the funding of research and services for that condition.<sup>[5]</sup> Elman

*et al.* found a much lower frequency of the word 'aphasia' in 50 US newspapers compared to other neurological conditions, such as Parkinson's disease (PD), but with lower incidence and prevalence than aphasia. A study 10 years later<sup>[6]</sup> analysed the quantity and quality of aphasia-related information in the English-only international written media in 1999 and 2009 and again compared it to PD. Although the frequency of aphasia-related items had increased four-fold between 1999 and 2009, it still occurred only once for every 27 PD-related mentions. Furthermore, the information provided was often sensationalist and inaccurate. Such findings emphasise the need

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to improve awareness and knowledge of aphasia in different communities; essential for improvement and extension of services and research, and to foster QoL and social inclusion for PWA in their communities.

Surveys around the world have attempted to measure levels of awareness and knowledge of aphasia in the public using telephone, internet and face-to-face surveys.

The UK-based lobbying charity *Speakability*<sup>[7]</sup> surveyed 1005 respondents by telephone controlled for class, age, sex and region. Respondents were simply asked what they knew of aphasia. Thirty-two (3%) gave an appropriate response. When provided with a basic definition of aphasia, 213 (21%) said they knew/had known, someone with aphasia, and this increased with age. This seems to suggest that although a significant proportion of the sample knew someone with aphasia, they did not know the term. Similar findings emerged from a telephone survey in Norway.<sup>[8]</sup> From a representative sample of 1000, 909 respondents had heard of stroke and 46% had heard of aphasia. Of this 46%, 60% knew that aphasia involved speech problems – the second most frequently mentioned impairment when asked to identify any impairment accompanying a stroke. Even fewer associated comprehension problems (27%) or reading/writing problems (6%) with aphasia; 24% of those who knew the word had knowledge of what aphasia was. A more recent UK telephone survey with a sample of 2000<sup>[9]</sup> found 90% had never heard of aphasia and 79% could not distinguish aphasia from a ‘skin disease’ or ‘a fruit’. An internet survey of 1142 in the US<sup>[10]</sup> aged over 25 found that 965 (84.5%) had never heard the term and 177 (15.5%) had. These 15.5% were asked to qualify their response and 101 (8.8%) answered appropriately. Of them, 35 (34.7%) knew someone with aphasia or had aphasia themselves (2.2%) and 30% had heard of aphasia through the media.

Assessing awareness levels has also entailed convenience face-to-face surveys in a community context in different countries. Most have used the same or similar methodology based on the questionnaire developed by Code *et al.*<sup>[11]</sup> Unlike the telephonic surveys, these surveys have sought more detailed information and been conducted with unselected convenience samples within a community.

### International Patterns of Aphasia Awareness and Knowledge

The earliest studies<sup>[11,12]</sup> interviewed 978 people in city centres in England, the USA and Australia using the same questionnaire. Respondents were asked if they had heard of aphasia; if they had, they were asked questions to determine *how much* they knew about aphasia and *where* they had heard about aphasia. Thus, they attempted to distinguish between levels of *knowledge* of aphasia from basic *awareness*. Of the 978 surveyed across the three countries, 136 (13.9%) claimed had heard of aphasia. However, only 53 (5.41%) had a basic knowledge of aphasia.

Similar face-to-face surveys in city centres using the same or similar methodology have been conducted in England,

New Zealand, India, Canada, USA, Singapore, Serbia and Montenegro and Sweden.<sup>[13-22]</sup> In addition, a large recent comparative study analysed surveys from Argentina, Canada, Croatia, Greece, Norway and Slovenia.<sup>[23]</sup> Ongoing surveys are taking place in Brazil, Ghana, Ireland and the USA.

Flynn *et al.*<sup>[13]</sup> compared awareness of aphasia and PD in the UK in a small sample of 100 members of the public and 26 friends or relatives of PWA. The combined sample again showed a significantly higher awareness of PD. As would be expected, relatives/friends had a significantly higher knowledge of aphasia and a significantly higher level of understanding of PD. Surprisingly, aphasia awareness in relatives/friends was not much greater than for PD (PD = 8.94; aphasia = 9.81). The researchers asked where respondents had heard about aphasia and PD, and for both conditions, the main source was the media, followed by a personal connection.

McCann *et al.*<sup>[14]</sup> recruited 300 respondents in New Zealand to compare awareness and knowledge of aphasia, PD and stroke in the general public and 100 healthcare professionals. Information was collected on age, sex and employment status. In all, 30% had heard of aphasia and 8% had basic knowledge. Just 11% of the general public (200) had heard of aphasia and only 1.5% had knowledge. In contrast, 68% of health professionals had heard of aphasia and 21% had basic knowledge. The public awareness of aphasia (11%) was significantly lower than awareness of PD (96%) and stroke (99.3%), and knowledge of aphasia was significantly lower than knowledge of PD (31.3%) and stroke (53.3%).

A small study in Kottayam in the south-eastern state of Kerala, India<sup>[15]</sup> interviewed 114 respondents: 11% had awareness and 8.7% had knowledge of aphasia, similar to those of other literate regions worldwide, although services for aphasic people are relatively limited in India. A sample of 114 is very small and unrepresentative of the population as a whole, and awareness in other parts of India are likely to be different.

A survey in Denton, Texas, USA<sup>[17]</sup> of 261 respondents found 44% had heard of aphasia, one of the highest awareness levels yet reported, but 7.6% had basic knowledge, which is comparable to other surveys. Similar surveys in Serbia and Montenegro<sup>[19]</sup> found that 12% (Serbia) and 11% (Montenegro) had heard of aphasia, but just 4% (Serbia) and 3.2% (Montenegro) had basic knowledge. In Sweden,<sup>[19]</sup> 372 respondents were surveyed and 247 (66%) had heard of aphasia, the highest level of awareness so far surveyed. Additionally, 64 (17% of respondents) had basic knowledge, as the highest surveyed worldwide.

A study in Galway, in the west of Ireland,<sup>[20]</sup> surveyed 600 respondents using the same questionnaire and methodology of other studies. Awareness was found in 19.7% and 5.7% had some basic knowledge. These findings are comparable to levels found elsewhere.

Another small study took place in Singapore<sup>[21]</sup> of 100 members of the public in a hospital lobby and 50 neurological ward staff.

In all, 14% of the public had heard of aphasia and 78.6% had knowledge. Among the ward staff, 96.7% had heard of the condition and 96.9% had basic knowledge. These figures, from a highly selective small sample, are difficult to interpret. The figures for the neurology ward staff would be expected, but the authors point out that the 100 members of the 'general public' probably included hospital staff and students.

The low levels of awareness and knowledge worldwide is highlighted by a recent large comparison of six countries in three continents using the same methodology.<sup>[22]</sup> These were Argentina (N = 800), Canada (N = 831), Croatia (N = 400), Greece (N = 800), Norway (N = 251) and Slovenia (N = 400). A total of 3483 were surveyed in community settings. Between 60% (Croatia) and 16% (Slovenia) had heard of aphasia (37.1% overall), with knowledge ranging from 13.9% (Norway) to 1.0% (Argentina). The combined mean of those with basic knowledge was 9.2%. Overall, those with awareness were younger and female. Associations between socio-economic status and awareness were also found: those working in health, social and educational spheres had the highest levels, mainly aware of aphasia through the media, work or personal contact with aphasia.

These data were compared with that collected in 2002 by Simmons-Mackie *et al.*<sup>[12]</sup> Using the same methodology, 978 were surveyed in Australia (N = 159), England (N = 378) and the USA (N = 441). The combined total was 4461 and the mean level of basic knowledge was 7.16% (range 1%-13.9%). A combined mean percent of 30.53 (range 11.95%-60%) had heard of aphasia. As might be expected, there was a significant variation between countries in awareness and knowledge. For example, Croatia had the highest awareness and Australia had the lowest, but very similar levels of knowledge.

To summarise so far, the awareness of aphasia is significantly lower compared to the awareness of other neurological conditions, such as PD. There is also a consistently significant difference between awareness of aphasia and knowledge. Table 1 depicts the proportions in each country with awareness and knowledge of aphasia by country. Significant variability is shown between countries.

Just one study has used one location to reassess whether aphasia awareness has changed over time. The value of such a study is

that it should show whether levels of awareness and knowledge are changing over time and also provide indications of what may influence change. The study was conducted in the city of Exeter, England (population of 100,000), 16 years after the first study.<sup>[24]</sup> The same methodology at the same site (a large shopping centre in the city) was used and the questionnaire was augmented with additional questions. In the intervening time a self-help group and other groups for PWA were established by the National Health Service. There had been some local radio and newspaper coverage of these groups' activities, but little other promotion of aphasia in the local media.

In 2016, 167 shoppers (378 in 2001<sup>[12]</sup>) were surveyed. Questions about awareness of stroke, stuttering, dyslexia and autism were included for comparison. Ethnicity and cultural background has been identified as a potential predictor of aphasia awareness in the UK,<sup>[14]</sup> so questions about ethnic/cultural origins were included. Of the 167 surveyed, 34% had heard of aphasia (18% in 2001, a significant increase) and 5% had basic knowledge (7.67% in 2001, non-significant decrease), suggesting that awareness of aphasia in the city had improved significantly, but knowledge had not. As found in 2001, awareness was highest in professional groups and in healthcare workers as well as in those who knew someone with aphasia. Awareness was higher in older respondents, but not knowledge. And awareness was significantly lower than that of all other conditions surveyed.

### Interactions between sex, age, socio-economic status and education and awareness of aphasia

Most surveys have examined demographic variables, levels of awareness and knowledge, and significant interactions have been observed as well as marked variability, already noted.

### Sex

In English-speaking countries,<sup>[12]</sup> females were significantly more likely to report awareness, but no significant differences between the sexes in knowledge. More females than males participated in the recent international comparison.<sup>[22]</sup> Females had significantly higher levels of awareness and more than twice as many females had knowledge compared to males; a significant difference. However, females were significantly younger than males (female mean 41.27, male mean 44.36)

**Table 1: International comparison of basic knowledge in face-to-face surveys**

Study	Location	Awareness (%)	Knowledge (%)	Sample Size
Code <i>et al.</i> , 2001	Exeter (UK) Louisiana (USA) Sydney (Australia)	13.7	5.07	929
Simmons Mackie <i>et al.</i> , 2002	As Code <i>et al.</i> , 2001 plus California	13.6	5.4	978
Chazhikat <i>et al.</i> , 2012	Kerala (India)	11	8.7	114
McCann <i>et al.</i> , 2013	New Zealand	30	8	300
Patterson <i>et al.</i> , 2015	Ontario (Canada)	31.8	5.7	831
Code <i>et al.</i> , 2016	Argentina, Canada, Croatia, Greece, Norway, Slovenia	37.1	9.2	3483
Vuković <i>et al.</i> , 2017	Serbia, Montenegro	11.5	3.5	900
Fahrenthold <i>et al.</i> , 2015	Denton, TX (USA)	44	7.6	241
Henricksson <i>et al.</i> , 2018	Sweden	66	17	372
Hill <i>et al.</i> , 2019	Exeter, UK	34	5	167

and age, rather than sex, may partly account for the higher levels of awareness and knowledge.

Significantly more females had awareness than males in Serbia-Montenegro,<sup>[18]</sup> In Serbia, of those who had awareness, 56.25% were female and 43.75% were male (non-significant). A similar association between sex and knowledge in the Serbian sample was not significant. In Montenegro, significantly more females (67.27%) than males (32.72%) had awareness, but again non-significant. In Sweden,<sup>[19]</sup> no significant associations were found between sex and awareness but in Ireland sex emerged as a significant factor.<sup>[20]</sup>

More surveys have found that females have significantly higher levels of awareness and knowledge, but this is not a universal finding. Females may have better awareness and knowledge of aphasia in most studies because females are more likely in occupations where they come into contact with people with aphasia.

### Age

Age is a significant factor associated with levels of awareness and knowledge of aphasia worldwide and the age ranges that have been sampled have differed between countries, significantly in some instances. For example, the combined mean age of the Code *et al.*<sup>[22]</sup> samples from six countries was 39.98 with a wide range (15-90). There were also significant differences between the mean ages sampled in each country and interactions were observed between levels of knowledge with age and country. In the same study, younger respondents were more likely to know about overall, but respondents with knowledge were significantly older (mean difference = 9.02 years) in the Greek sample. Of those who had no knowledge but had awareness, Norwegians and Greeks were significantly younger. In Canada,<sup>[16]</sup> those who had awareness were significantly older (49.5 years) than those who had not. Norwegians, Greeks and Croatians with awareness were significantly younger than in other countries. Overall, for the Code *et al.* study, however, there were significant interactions between age and knowledge. In contrast, for all English-speaking surveys,<sup>[12]</sup> respondents with awareness were significantly older than those without, but there were no significant differences in age for those with knowledge.

In Serbia, younger respondents were significantly more likely to have awareness than younger respondents in Montenegro. But younger respondents were significantly more likely to have knowledge in Montenegro, unlike in Serbia where no association was found between age and knowledge. In Sweden,<sup>[19]</sup> where the highest levels of awareness and knowledge have been recorded, older individuals had higher levels of awareness than younger respondents and more than half of the Swedish respondents who had no awareness were aged within 18-35 years with those with awareness mainly aged within 66-75 years.

In summary, age appears to be a significant predictor of levels of awareness and knowledge of aphasia. However, in different

investigations, with different populations, age has not always been shown to be a reliable predictor.

### Socio-economic status and education

Significant, but variable, interactions between socio-economic group and awareness have been found, with those in socio-economic groups I (higher professions, e.g., physicians, lawyers and architects) to III (skilled workers) having higher levels of awareness.<sup>[22]</sup> In the Simmons-Mackie *et al.*<sup>[12]</sup> study, socio-economic groups II (e.g., teachers, nurses and social workers) and VI (e.g., retired and students) were more likely to have awareness, but socio-economic grouping did not interact significantly with knowledge. However, the study did not record the pre-retirement occupations of retired respondents. It appears that those engaged in occupations where they were more likely to come into contact with people with aphasia (e.g., healthcare professionals and social workers) and are more likely to have knowledge.<sup>[16]</sup> Similarly, the occupation was a factor in the surveys carried out in Ireland,<sup>[20]</sup> with the same group II emerging as most knowledgeable.

In the recent Exeter study,<sup>[24]</sup> particularly group VIII (retired) had higher awareness and knowledge. Post-hoc examination of pre-retirement occupations showed that over two-thirds were from socio-economic group II (e.g., teachers, social workers and healthcare workers), appearing to confirm the significant relationship between awareness, knowledge and socio-economic circumstances.

Likewise, higher levels of basic knowledge in Montenegro were associated with groups I and II. In Serbia again there were markedly more respondents from group II with knowledge, with a small spread in other groups who also had knowledge. Educational levels are closely associated with socio-economic group, and the Balkans study<sup>[18]</sup> collected data on educational background. The majority of the combined Serbia-Montenegro sample (94%) had the education to High School (59.7%) or undergraduate degree (35%) levels, and there were significant associations between education and awareness: those with a degree were more likely to have awareness than those with High School education, but there was no significant difference in knowledge between those with a degree and those with High School education.

Summarising the influence of demographic variables, females have higher levels of knowledge across studies than males, and in some studies, older respondents are more likely to have awareness, and younger one's better knowledge. Occupation and education also influence levels of knowledge and those with higher socio-economic status and education are more likely to have better knowledge. Most clearly emerging from the data is that intermediate professions, who are more likely to have been in contact with people with aphasia, have the highest levels of awareness and knowledge.

As noted above, a marked feature across studies is variability, which is apparent within as well as between countries. For instance, in the USA,<sup>[12]</sup> significant differences between

California (awareness = 17.30%; knowledge = 11.53%) and Louisiana were found (awareness = 9.25%; knowledge = 1.54%) and the recent study in Texas<sup>[17]</sup> found that respondents had a basic knowledge of 7.6% and one of the highest levels of awareness of aphasia (44%). Louisiana has significantly lower socio-economic and educational levels than California and Texas, and it seems probable; therefore, that socio-economic and educational factors were responsible for some of the differences found between these three American states.

### Sources of awareness and knowledge of aphasia

Analyses of sources of knowledge show consistent findings across the world. Most respondents acquire their awareness and knowledge from the media (radio, TV, newspapers, magazines, etc.), their work (health professionals, social workers, etc.) or because they have or had a relative or friend with aphasia. In the six countries surveyed,<sup>[22]</sup> for instance, 36.5% had awareness through the media, 20% through their work and 14.6% because they knew someone with aphasia. These figures are detailed for each country, including the English-speaking countries surveyed by Simmons Mackie *et al.*,<sup>[12]</sup> in Figure 1. For Greece, particularly, an overwhelming proportion came across aphasia in the media.

### Raising the public awareness and knowledge of aphasia

Findings provide a basis for efforts to raise awareness and improve knowledge of aphasia. Occupational groups and service providers who come into regular contact with PWA can be successfully trained to improve their communication and there have been a few systematic attempts to increase understanding of aphasia in some occupational groups, especially the emergency services. An example is Baig<sup>[25]</sup> who developed a brief awareness programme for 47 first responders (i.e., police, medical technicians, fire fighters, etc.). A PowerPoint presentation and a video were developed to improve communication with a PWA. Testing after training suggested a marked improvement in levels of awareness. Similarly, Ranta<sup>[26]</sup> developed an 120-minute awareness programme also using video and PowerPoint for emergency

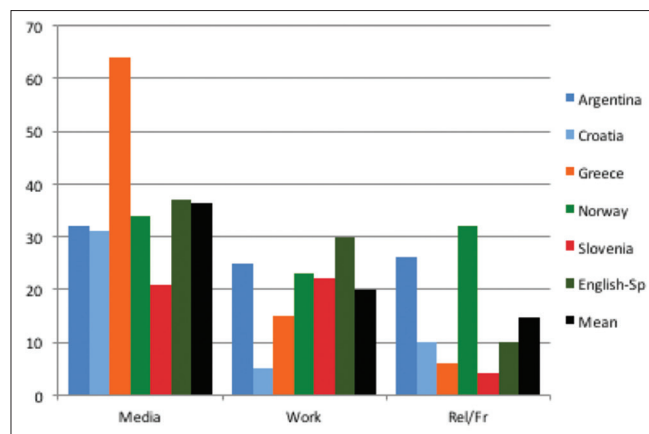
responders in association with a PWA. Post-training testing showed a significant improvement in understanding of aphasia. A six-week programme to improve the communication of police officers in Sydney, Australia during routine telephone encounters with people with communication problems following traumatic brain injury (TBI) was conducted.<sup>[27]</sup> After training, officers had learned strategies to establish the nature of an inquiry, provide clearer answers for people with TBI and provide more efficient, focused communications. People with TBI altered their communication too, reduced the amount of unrelated and irrelevant speech and increased the number of interactions dedicated to the successful completion of their interactions.

PWA seem to come into contact with shop assistants, restaurant workers, bank tellers and the general public more than they do with healthcare and social workers<sup>[28]</sup> and people with awareness through the media represent those in the community with no previous knowledge of aphasia before they had come across it through TV/radio or print. Findings provide some clues as to *where* to aim awareness-raising and *to whom*. As noted above, awareness in Sweden is the highest yet recorded and most Swedish respondents gained awareness through the media. A campaign was launched in Sweden in 2011 where healthcare regions and county councils informed the public of, for example, symptoms that may indicate a stroke, which may explain why a relatively high percentage of the Swedish sample had awareness. It also argues for the relevance of media-based awareness-raising.

It will be remembered that the lowest awareness levels recorded were in Argentina. This prompted a wide ranging programme of awareness-raising: a booklet about how to manage PWA and a brochure explaining what aphasia is was prepared and distributed at the Neurology Services in Buenos Aires hospitals. A series of radio and TV programmes on aphasia were broadcast and newspaper articles were published, posters were placed in the streets of Buenos Aires and two 30-second films were shown on TV, cinemas and public transport.

Even short programmes of awareness training have the potential to reduce frustration and improve community access for PWA and their experience of community interaction. The questionnaire described in this article can be easily adapted to survey awareness within a community, a small town, an occupational group, or a department store followed by an awareness campaign. Post-campaign surveying, examining the impact of the programme could also be conducted. Such investigations can also be extended to map levels of awareness within a single community over significant periods.

A recent article<sup>[23]</sup> provided some suggestions for future work on raising awareness. It suggested utilising established marketing and health promotion practice and theory and suggested that awareness-raising should involve people with aphasia and their families in the design of campaigns.



**Figure 1:** Where and how respondents had heard of aphasia (Rel/Fr = Relative or Friend)

## CONCLUSIONS

Results of a large range of international surveys reinforce the finding that levels of awareness are low in all countries in absolute terms, and also related to awareness of other conditions. Significant variability exists between and within countries and studies, and in the impact of demographic factors, with some significant cross-cultural differences. One implication of these findings is that awareness-raising can be guided and targeted at specific service providers and occupational groups and sections of the community. However, caution should be practiced in generalizing findings to national and international populations from small studies. Future studies can also examine ethno-geographical variation in awareness in more detail, within and between multi-cultural countries. The methodology and questionnaire described in this paper can be adapted and used to examine awareness and knowledge within a community in combination with an awareness-raising or educational programme.

In most countries those with knowledge of aphasia gain their knowledge mainly from the media, which can reach large audiences and exploit awareness-raising. Web-based social media too, can reach large numbers. The future awareness-raising programmes should make use of the methods adopted by public health and marketing.

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## Conflicts of interest

There are no conflicts of interest.

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## APPENDIX: AWARENESS OF APHASIA QUESTIONNAIRE

The standard questionnaire records information on age, sex and occupation. Occupations are ultimately converted into socio-economic groups defined by the UK Classification of Occupations of the Office of Population Censuses and Surveys, but other socio-economic systems used in other countries can be used instead. The widely used UK system classifies individuals based on five occupational categories: I - Professional (e.g., physicians, lawyers, academics and engineers); II - Intermediate (e.g., administrators, managers, school teachers, nurses, middle-rank civil servants, speech and language therapists and physiotherapists); IIIN - Skilled (or junior) non-manual (e.g., shop assistants, clerical and secretarial); IIIM - Skilled manual (e.g., electricians, carpenters, butchers, chefs/cooks and bus/train drivers); IV - Partly skilled manual (e.g., bus/train conductors, agricultural workers and postmen); V - Unskilled manual (e.g., cleaners, dockers and labourers). These five were augmented by two additional categories in some studies covering: VI - unemployed and students; VII - Retired. Respondents who were retired or unemployed were further classified by their last occupation.

Respondents are asked if they have heard of aphasia or dysphasia. For those who say they had heard of it, their knowledge is tested by asking them to choose from a list of features, which are provided verbally by the interviewer. This list includes features that are not indicative of aphasia. A respondent is considered to have some *basic knowledge of aphasia* if they select either 'speech', 'language' or 'communication problems' (or two of these or all three) together with 'brain damage or injury'. They can also choose to include problems with *reading, writing and understanding*, but the choice of one or all three of these features is insufficient on their own to be classed as *basic knowledge*. There are also foil questions asking respondents if aphasia involves 'impaired intelligence', and 'mental' problems. If respondents say that they have heard of aphasia they are asked *where* they had heard of aphasia, and if anything could be done for people with aphasia.

The original English version of the questionnaire is reproduced as an appendix in Simmons-Mackie *et al.*<sup>[12]</sup> and is freely available from the author of this paper.