Addressing the language barriers to inclusion in paediatric emergency medicine research

Hannah Walsh,[1] Silothabo Dliso,[2] Shrouk Messahel 🄳 [1]

[1]Department of Paediatric Emergency Medicine, Alder Hey Children's NHS Foundation Trust, Liverpool, UK
[2]Department of Paediatric Research, Alder Hey Children's NHS Foundation Trust, Liverpool, UK

Correspondence to
Dr Shrouk Messahel, Emergency Department, Alder Hey Children's Hospital, Liverpool, L12 2AP, UK; Shrouk. Messahel@alderhey.nhs.uk

Check for updates

INTRODUCTION

There are many challenges to ensuring good representation within a research study, one such challenge is spoken language.[1] In countries where the primary spoken language is English, such as the UK, it has been observed that people who require translation services are frequently excluded from participating in research studies.[2–5]

The implications of language-based exclusion in research are that essential data could be missed; including how different groups of people present clinically in relation to disease, or differences in responsivity to treatments.[6–9] Exclusion based on language ability has the potential to lead to greater disparities in health outcomes, as well as limiting the generalisability of the study outcomes.[9] In addition, children from households that express limited comfort with communication in English are more likely to experience higher communication-related adverse events, medical errors and mortality.[10–12]

Paediatric emergency departments are ideal environments from which to recruit people for health research. They facilitate recruitment at first presentation as well as the recruitment of people who are not ultimately admitted or who may not require follow-up within the hospital.[13] They act as the interface between primary and secondary care, and are a vital safety net.[14] Emergency departments are potentially the area where there is the most diversity in a single healthcare setting regarding demographics of people and the conditions and severity they may present with.[13]

Research practices regarding language inclusivity in paediatric emergency medicine (PEM) research are not well documented. Moreover, there is limited data regarding exclusion from research based on language ability in general medical literature in the UK. Here, we explore current research to identify practices around language inclusivity in research, and what challenges researchers face including people requiring translation services.

EVIDENCE OF PROBLEM

English language skill has been shown to be a valid indicator of health status in the UK.[15] The UK 2011 census revealed that only 65% of people who were not proficient in the English language were in good health, compared with nearly 88% with English as their main language.[16 17] The areas in the UK where the disease burden is the greatest also have the lowest participation rates in research, with language barriers being cited as one of the three primary reasons for the underrepresentation observed.[18]

Most research investigating language-based exclusion in clinical research is based in the USA, and in the adult population. Reviews of articles in major US journals and study protocols from the last four decades show that language ability was a common reason for exclusion and that there is a potential rise in the trend of exclusionary practice based on language.[2–4] One review that included UK studies found that 84% of articles did not discuss language issues at all.[5]

UK data are limited, and no studies or reviews have been found that explore language-based exclusion in PEM research. A review from the USA of >5000 paediatric research articles published between 2012 and 2021 found that only 9% of studies included people who required translation services.[19]

Language-based exclusion contributes to the lack of diversity in participant population and for PEM, this risks an

Table 1	Brislin's back translation model
Step 1	Forward translation: a translation of the document from the language it was originally written into the new language of choice.
Step 2	Backward translation: a second translator, without having seen the document in its original language, independently translates the document from the new language of choice back to the original language.
Step 3	To measure accuracy the back-translated document is checked against the original document.
Step 4	Any questionable items or errors in the back-translated version are identified. A different translator then independently translates these sections.
Step 5	The process repeated until the back-translated document is shown to represent the original document accurately.

evidence base which does not account for the disease burden according to background and heritage, as well as potentially fails to include an at-risk and vulnerable group of children.[1 16 17]

WHAT ARE THE BARRIERS

Paediatric emergency departments have unique challenges surrounding seeking consent for clinical research in situations that can be sensitive and time limited.[20] Even when it is possible to be language inclusive, it may be difficult to accommodate all languages due to the unpredictable nature of emergency departments. Moreover, there is evidence to suggest that in PEM, interpreters for clinical purposes are used less as the department becomes busier, this may also impact clinical research.[21]

Ensuring quality of translation could be another barrier as interpretation and translation are not statutorily regulated and there are no universal standards that have to be followed, meaning that quality control across services may vary and translation agencies do not have to provide someone qualified.[22] This contrasts with the clear standards that exist within research for data collection, analysis and interpretation.[22–24] It is the responsibility of individual researchers to assess the quality of the service they intend to use.[25] This could potentially be a time consuming and daunting task and may be difficult to complete depending on the resources available.

Even where resources are available and rigorous processes have been followed, studies have shown that the way in which a word or phrase is translated according to a regional and cultural variations can significantly alter the study's findings.[22 26] Translators need to consider the participants' country of origin and the context of the phrase within regional variations.

The potential increase in cost that interpretation and translation may add to a research study could be prohibitive.[27] The cost of obtaining culturally and linguistically accurate translations, in time, money and resources, may not be justifiable depending on factors such as how often the service is likely to be used.

POTENTIAL SOLUTIONS

To facilitate further exploration and learning around language inclusion, researchers should be encouraged to discuss linguistic diversity of the research population, how translation occurred and any barriers to inclusion. This would highlight any potential biases in the interpretation of the research findings, as well as helping to identify barriers and facilitators to being language inclusive on a larger scale.

To ensure that time, money and resources are allocated appropriately, language needs in clinical research should be considered during the planning stage by both investigators and funding agencies.[25] This includes a language and literacy assessment of the study population, enabling researchers to determine demand, which would then inform a more precise cost-benefit valuation for the use of translation services within the study.[25 28] The National Institute for Health and Care Research (NIHR) advises that the percentage of the target population that relies

Table 2	Core problems and potential solutions to address the language barriers to inclusion in paediatric emergency medicine research	
	Problems	**Solutions**
Written translation	Unpredictable nature of paediatric emergency departments makes it difficult to accommodate for all potential languages. Time required to produce translated documents which have conceptual equivalence. Ensuring conceptual equivalence of written translation.	Consider language needs at the planning stage with adequate Patient and Public Involvement (PPI) representation. Language and linguistic assessment of study population. Use of research tools such as INCUDE and HIAT to assist planning. Use of frameworks such as Brislin's back translation model.
Verbal translation	Timely access to qualified translators in an emergency setting.	Opportunity for bilingual staff members to train in research consent. Cautious consideration of the use of family members, ensuring NIHR guidance is followed.
Both	No universal standards for ensuring quality control across translation services. Regional or cultural variations within a language. Cost of translation services.	Clear universal standards for translators used in clinical research. Co-production of work with community representation. Use of research tools such as those provided by NIHR, at the study conceptualisation phase.
NIHR, National Institute for Health and Care Research.		

on interpreters should be reflected in the proportion of people who do not speak English included in the study.[25]

National funding bodies in the UK have developed guidelines and frameworks aimed at improving inclusion in clinical research.[1 29] Frameworks such as INCLUDE and HIAT provide tools to guide improved inclusion of underserved communities and reduce health inequalities in research.[1 30] The NIHR has also produced a two-part guide on how to conduct research involving interpreters and translators, and how to calculate the associated cost.[25 31]

For ethical approval, the Health Research Authority (HRA) offers guidance on their integrated Research Application System for approvals and permissions. This outlines requirements for applications where translation services are to be used in a study.[32] Proposals for translation will be considered by the Ethics Committee as part of the application process.[32] Email correspondence with the HRA confirmed that translated versions of documents do not need to be submitted with the applications, and for ongoing studies, amendments can be submitted detailing what provisions are in place for the use of translation services.

Where written translation is required, methods such as Brislin's back translation model are advised to ensure equivalency between the original and translated text (table 1).[18 28 33 34] Where possible, interpreters should have awareness of regional and cultural differences.[18 26 35] Having an accepted standard or qualification for research translators would hold translation agencies accountable to a minimal standard and reduce the workload for researchers. Table 2 (table 2) summarises the core problems and potential solutions in language inclusivity research.

When researchers do not have access to translation services, more readily available and free services such as Google Translate are advised against due to the high risk of errors and lack of confidentiality regulations.[36 37] The Department of Health and Social Care advises against the use of family members for translation for clinical care.[37 38] Given the unpredictable nature of emergency departments, family members are often more immediately available and may be helpful in providing cultural context for translation for research participation in an emergency setting. However, a balanced consideration is vital, and the NIHR cautions that if family members are used, then the integrity of the translated response need to be considered, as well as ensuring that private and confidential information is protected.[18] Bilingual healthcare providers can be useful in translating for patients in emergency clinical situations.[39] While professional standards of clinical care may make this more acceptable than using family members, they would still need appropriate training in research consent.

CONCLUSION

This review has highlighted some of the challenges to including people requiring translation services in PEM research, as well as identifying potential solutions and guidance which currently exist but may not be common knowledge.

The existing guidance and resources are helpful and provide a foundation on which to build on. However, more evidence needs to be gathered to help shape best practice and develop strategies, frameworks and resources that are accessible to all and sustainable. This needs to be context specific, acknowledging that certain environments, such as the emergency department, are more difficult to plan for given their unpredictable nature and may require more innovative solutions.

ORCID iD
Shrouk Messahel http://orcid.org/0000-0003-0645-3070

REFERENCES

1 National Institute for Health Care Research. Improving inclusion of under-served groups in clinical research: guidance from INCLUDE project. 2020. Available: https://www.nihr.ac.uk/documents/improving-inclusion-of-under-served-groups-in-clinical-research-guidance-from-include-project/25435 [Accessed 02 Nov 2021].

2 Frayne SM, Burns RB, Hardt EJ, et al. The exclusion of non-English-speaking persons from research. *J Gen Intern Med* 1996;11:39–43.

3 Brodeur M, Herrick J, Guardioloa J, et al. Exclusion of non-English speakers in published emergency medicine research - A comparison of 2004 and 2014. *Acta Inform Med* 2017;25:112.

4 Egleston BL, Pedraza O, Wong Y-N, et al. Characteristics of clinical trials that require participants to be fluent in English. *Clin Trials* 2015;12:618–26.

5 Murray S, Buller AM. Exclusion on grounds of language ability – a reporting gap in health services research? *J Health Serv Res Policy* 2007;12:205–8.

6 Beard E, Dixon S, Rai T, et al. Ethnicity and socioeconomic status: missing in research means missing in clinical guidance. *BJGP Open* 2021;5:BJGPO.2021.0034.

7 Wales JA, Palmer RL, Fairburn CG. Can treatment trial samples be representative? *Behav Res Ther* 2009;47:893–6.

8 Treweek S, Forouhi NG, Narayan KMV, et al. COVID-19 and ethnicity: who will research results apply to? *Lancet* 2020;395:1955–7.

9 Varma T, Jones CP, Oladele C, et al. Diversity in clinical research: public health and social justice imperatives. *J Med Ethics* 2023;49:200–3.

10 Khan A, Yin HS, Brach C, *et al*. Association between parent comfort with English and adverse events among hospitalized children. *JAMA Pediatr* 2020;174:e203215.

11 Yin HS, Mendelsohn AL, Wolf MS, *et al*. Parents' medication administration errors. *Arch Pediatr Adolesc Med* 2010;164.

12 Anand KJS, Sepanski RJ, Giles K, *et al*. Pediatric intensive care unit mortality among latino children before and after a multilevel health care delivery intervention. *JAMA Pediatr* 2015;169:383–90.

13 Kendrick D, Lyons R, Christie N, *et al*. Recruiting participants for injury studies in emergency departments. *Inj Prev* 2007;13:75–7.

14 RCEM Special Interest Group. Position statement on public health in emergency medicine. 2021. Available: https://rcem.ac.uk/wp-content/uploads/2021/10/Combined_PH_Role_Description_and_Position_Statement.pdf [Accessed 17 Nov 2021].

15 Jill Roberts Public Health England. Local action on health inequalities. improving health literacy to reduce health inequalities. practice resource summary. 2015. Available: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/460710/4b_Health_Literacy-Briefing.pdf [Accessed 17 Nov 2022].

16 Census 2011. People who cannot speak English well are more likely to be in poor health. 2015. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/language/articles/peoplewhocannotspeakenglishwellaremorelikelytobeinpoorhealth/2015-07-09 [Accessed 18 Aug 2022].

17 Peter Stokes. Census: detailed analysis - English Langauge proficiency in England and Wales, main language and general health characteristics. 2013. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/language/articles/detailedanalysisenglishlanguageproficiencyinenglandandwales/2013-08-30 [Accessed 20 Oct 2022].

18 NHS England. Increasing diversity in research participation: a good practice guide for engaging with underrepresented groups. 2023. Available: https://www.england.nhs.uk/aac/publication/increasing-diversity-in-research-participation/ [Accessed 15 Apr 2023].

19 Chen A, Demaestri S, Schweiberger K, *et al*. Inclusion of non–English-speaking participants in pediatric health research: a review. *JAMA Pediatr* 2023;177:81–8.

20 Graham CA. Barriers to research in emergency medicine. *Eur J Emerg Med* 2019;26:149.

21 Hartford EA, Anderson AP, Klein EJ, *et al*. The use and impact of professional interpretation in a pediatric emergency department. *Acad Pediatr* 2019;19:956–62.

22 Lopez GI, Figueroa M, Connor SE, *et al*. Translation barriers in conducting qualitative research with Spanish speakers. *Qual Health Res* 2008;18:1729–37.

23 O'Brien BC, Harris IB, Beckman TJ, *et al*. Standards for reporting qualitative research: a synthesis of recommendations. *Acad Med* 2014;89:1245–51.

24 Butcher NJ, Monsour A, Mew EJ, *et al*. Guidelines for reporting outcomes in trial reports: the CONSORT-outcomes 2022 extension. *JAMA* 2022;328:2345–56.

25 Shelley Purchon. How to calculate the costs of involving interpreters and Translators in health and social care research [National Institute for Health and Care Research]. 2022. Available: https://arc-nenc.nihr.ac.uk/wp-content/uploads/2022/12/Guide-Part-One-How-to-calculate-the-costs-of-involving-interpreters-and-translators.pdf [Accessed 19 Apr 2023].

26 Twinn S. An exploratory study examining the influence of translation on the validity and reliability of qualitative data in nursing research. *J Adv Nurs* 1997;26:418–23.

27 Squires A, Sadarangani T, Jones S. Strategies for overcoming language barriers in research. *J Adv Nurs* 2020;76:706–14.

28 Willis A, Isaacs T, Khunti K. Improving diversity in research and trial participation: the challenges of language. *Lancet Public Health* 2021;6:e445–6.

29 Wellcome Trust. Wellcome trust clinical trials policy. 2021. Available: https://wellcome.org/grant-funding/guidance/clinical-trials-policy [Accessed 19 Apr 2023].

30 NIHR Applied Research Collaboration North West Coast. Health inequalities Assessment toolkit. 2023. Available: https://arc-nwc.nihr.ac.uk/resources/hiat/ [Accessed 12 Aug 2023].

31 Shelley Purchon. How to conduct research involving interpreters and Translators [NIHR Applied Research Collaboration (ARC). 2022. Available: https://arc-nenc.nihr.ac.uk/wp-content/uploads/2022/12/Guide-Part-Two-How-to-conduct-research-involving-interpreters-and-translators.pdf

32 Integrated Research Application System. Preparing and submitting applications - NHS/HSC R&D Permissions. 2022. Available: https://www.myresearchproject.org.uk/help/hlpnhshscr.aspx [Accessed 27 Apr 2023].

33 Brislin RW. Back-translation for cross-cultural research. *J Cross Cult Psychol* 1970;1:185–216.

34 Lee SS, Dinicu A, Arthurs L, *et al*. Ensuring equal access: language as exclusion criteria among clinical trials in gynecologic oncology. *JCO* 2022;40:e18587.

35 Bontempo R. Translation fidelity of psychological scales: an item response theory analysis of an individualism-collectivism scale. *J Cross-Cult Psychol* 1993;24:149–66.

36 Moberly T. Doctors are cautioned against using Google translate in consultations. *BMJ* 2018:k4546.

37 Office for Health Improvement and Disparities. Language interpreting and translation: migrant health guide. 2017. Available: https://www.gov.uk/guidance/language-interpretation-migrant-health-guide [Accessed 18 Nov 2022].

38 NHS England / Primary Care Commissioning. Guidance for commissioners: interpreting and translation services in primary care. 2018. Available: https://www.england.nhs.uk/wp-content/uploads/2018/09/guidance-for-commissioners-interpreting-and-translation-services-in-primary-care.pdf [Accessed 18 Nov 2022].

39 Lehane D, Campion P. Interpreters: why should the NHS provide them? *Br J Gen Pract* 2018;68:564–5.