INVITE Study- Evaluation of translation and interpretation services implemented by Clinical Trial Units to recruit Ethnic minority groups in trials

Thank you for your interest in this survey. It will only take about 15 minutes to complete.

What is the purpose of the study?
We are trying to assess how UK Clinical Trials Units (CTUs) currently implement and use Translation and Interpretation services to improve accessibility and inclusivity of Ethnic minority groups to take part in clinical trials research. This survey is part of a wider project called the INVITE Study which is funded by the National Institute of Health and Care Research (NIHR) and is led by researchers from the Universities of Bristol and Sheffield.

The 2021 UK census found that over 20% of people identified English as not their first language and described themselves as also not being able to speak English well or could not speak English at all. It is well known that language is one of the main barriers for people taking part in research but how this is being addressed is largely an under-researched area.

The aims of the INVITE Study are to understand current practices of Translation and Interpretation services being used in clinical trials and assess experiences and acceptability of using these services by clinical trial teams, NHS staff and patients. We would also like to assess value on the use of translation and interpretation services in trials through collecting resource and cost data.

Who should take part in this survey?
We would like to obtain data from all UKCRC CTU staff involved in designing or delivering clinical trials and have experience in implementing translation/interpretation services. This may include CTU Directors, Operations Managers, EDI Leads, Trial Managers or Trial Methodologists. We will welcome feedback from all who are involved as appropriate.

What will happen if I take part?
We will ask standard questions about your CTU's practice and experiences of using Translation and Interpretation services on an online survey. The survey will take no longer than 15 minutes to complete and as a thank you, you can choose to enter a prize draw to win a £50 Amazon voucher. We will also be happy to share the study findings with you.

The information you provide will be valuable in providing evidence that researchers and NHS staff can use to enhance inclusion in clinical trials in the future. We welcome thoughtful responses from everyone involved, whether directly or indirectly. If you're unsure about any questions, please feel free to discuss them with your team members. We are aware that some CTUs are very large therefore

we understand if you would like to provide more than one response (i.e more than one person per CTU responds to the survey). In this scenario, we may get in touch with you if some of the responses vary. This will only be for our clarification and if you have shared your e-mail address.

Would my taking part in this survey be kept confidential?
All information that we collect will be kept confidential and only direct members of the study team will have access. In the survey we will only ask if you are happy to provide your name and e-mail address to be entered into the prize draw, and to potentially contact you in the future. You do not have to share your e-mail address. If you do decide to share your e-mail address, it will not be connected to your survey responses. We will also ask separately, if you are happy to share any related materials (e.g SOPs or EDI Strategy documents) you may use and/or take part in a qualitative interview, again these will be optional and held separately from your responses. You can choose to simply complete the survey without providing your contact details.

If we collect your name, you will not be identified in any report, and we will ensure all responses received will be combined and presented as overall feedback and themes to maintain the confidentiality of each CTU taking part. All data collected in this survey will be handled in a lawful, fair and transparent manner, in accordance with the General Data Protection Regulation (GDPR) for health and care research, and in accordance with the Data Protection Act 1998. Data will be stored securely on the University of Bristol computing networks and destroyed after 10 years, in line with University of Bristol's retention policy for research data.

Who has reviewed this survey?
This survey has been independently reviewed by the Faculty of Health and Life Sciences Research Ethics Committee at the University of Bristol.

Consent to participate
By completing the survey, you agree to the terms set out above.
If you decide you do not wish to complete the survey, you can exit this page without any obligations.
If you have any questions or concerns about the survey, please contact us by e-mailing kirsty.roberts@bristol.ac.uk. If you have any complaints about this survey, then please contact research-governance@bristol.ac.uk. This will be reviewed by the independent team to the research team.

Thank you for taking time to read this information.

SECTION 1: EDI at your Clinical Trials Unit (CTU)

1. What is the name of your CTU? *

2. Is your CTU: *

- ◯ University based
- ◯ NHS based
- ◯ Both
- ◯ Other (please specify)

3. Which settings are your trials recruiting from *(please select all that apply)*? *

- ☐ Primary care
- ☐ Secondary care
- ☐ Emergency settings
- ☐ Social care
- ☐ Tertiary care
- ☐ Other (please specify)

4. Does your CTU have an EDI strategy? *

- ◯ No, and we don't have plans to develop one
- ◯ No, but would like to/ are thinking of developing one
- ◯ Yes
- ◯ Yes, but the EDI strategy is covered in the main CTU strategy
- ◯ Other (please specify)

5. Would you be willing to share the EDI strategy with the INVITE Study team? *(detail will be used for content analysis and the unit will not be identified in any dissemination material)* *

- ◯ Yes
- ◯ No

6. Do you have an EDI lead? *

- ◯ Yes
- ◯ No

7. Do you have an EDI Research committee/ group? *

- ◯ Yes
- ◯ No

8. Which of the following EDI strategies do you consider in your trials (*please select all that apply*)? *

- ☐ Including specific geographical areas/ sites to improve diversity of trial population
- ☐ Translation of study documents
- ☐ Interpretation services
- ☐ Translation and interpretation support for IMP participant management
- ☐ Community champions
- ☐ Community engagement events to raise study awareness
- ☐ Easy Read documents
- ☐ Video PILs (with language needs considered for underserved groups)
- ☐ Cultural Competency training for CTU staff
- ☐ Cultural Competency training for site staff/ included in SIVs
- ☐ Setting recruitment goals or targets for underserved populations
- ☐ Monitoring diversity of underserved groups at screening and recruitment
- ☐ Monitoring drop-out of underserved groups
- ☐ Translation of dissemination materials
- ☐ Holding dissemination community engagement events

- [ ] Costing in extra recruitment time for underserved groups
- [ ] Costing in extra set-up time for less research-ready sites
- [ ] Costing in extra time to support completion of follow up data
- [ ] None of the above
- [ ] Don’t know
- [ ] Other (please specify)

9. How do you **currently** apply these EDI strategies to the trials within the unit? *

Including specific geographical areas/sites to improve diversity of trial population

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Translation of study documents

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Interpretation services

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Translation and interpretation support for IMP participant management

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Community champions

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know

- [ ] Not applicable (we don't apply this EDI strategy)

Community engagement events to raise study awareness

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Easy read documents

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Video PILs (with langauge needs considered for underserved groups)

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Cultural competency training for site staff/ included in SIVs

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Setting recruitment goals or targets for underserved populations

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Monitoring diversity of underserved groups at screening and recruitment

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Monitoring drop-out of underserved groups

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Translation of dissemination materials

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Holding dissemination community engagement events

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Costing in extra recruitment time for underserved groups

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Costing in extra set-up time for less research-ready sites

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

Costing in extra time to support completion of follow-up data

- [ ] Apply this to ALL of our trials
- [ ] Apply this to SPECIFIC trials only
- [ ] Don't know
- [ ] Not applicable (we don't apply this EDI strategy)

SECTION 2: Translation and Interpretation

Please consider ALL trials within your CTU which are currently active, i.e recently funded through to being in the closedown process

10. How many of your trials have translated documents? *

- ◯ All
- ◯ Most
- ◯ Some
- ◯ None
- ◯ Don't know

11. How many of your trials have interpretation services included? *

- ◯ All
- ◯ Most
- ◯ Some
- ◯ None

12. If not ALL of your trials have translated documents and interpretation, why is this (*please select all that apply*)? *

- ☐ Not enough funding
- ☐ Too difficult
- ☐ In some cases, it was not a funder requirement
- ☐ Trials were funded before NIHR Inclusion requirement
- ☐ Not enough time
- ☐ Don’t think it is needed in all trials
- ☐ Other (please specify)

13. Following the NIHR's Inclusion requirement, are you now more likely to incorporate translated documents and interpretation into all of your trials? *

- ◯ Yes
- ◯ No

- ◯ Any further comments (please add)

14. If no, please state why (*please select all that apply*) *

- ☐ Some of our funders don't require this
- ☐ Some of our trials don't require this
- ☐ Other (please specify or add further details if you wish)

15. Which documents do you routinely translate (*please select all that apply*)? *

- ☐ PIL
- ☐ Easy-Read information leaflet
- ☐ Consent Forms
- ☐ Videos (audio script)
- ☐ Video (subtitles)
- ☐ Dissemination material
- ☐ Questionnaires/ PROMs
- ☐ IMP labelling/ instructions
- ☐ Participant diaries
- ☐ Not applicable, we don’t routinely translate study documents
- ☐ Other (please specify)

16. How many languages do you usually provide for translated documents? *

17. Have you been asked by a site to provide translated documents in a language which wasn’t pre-translated (i.e have you had requests for additional translations)? *

- ◯ Yes

- ◯ No

18. How often has this happened? *

- ◯ In all the trials
- ◯ In most of the trials
- ◯ In some of the trials
- ◯ In a few trials

19. How did you approach this request? *

20. Do you think the translated documents and interpretation are used by the majority of sites? *

- ◯ Yes
- ◯ No
- ◯ Not sure
- ◯

21. Please provide further details as to why you think they are not being used *(for each translated documents and interpretation)* *

22. Do you routinely measure how much they are used? *

Translated documents

- ◯ Yes
- ◯ No
- ◯ No, but we plan to

Interpretation services

- ◯ Yes
- ◯ No
- ◯ No, but we plan to

23. How do you decide which languages to translate the study documents into? *(select all that apply)* *

- ☐ Use most recent UK Census data
- ☐ Use disease registries/ audits
- ☐ Survey sites for most commonly spoken languages
- ☐ Other (please specify)

24. Do you carry out any of the following validation checks when translating study documents? *(please select all that apply)* *

- ☐ Translatability check (can be carried out before translation to assess how easily the document can be translated into multiple languages)
- ☐ Provide extra information about the trial and context to translation services before translation
- ☐ Back-translation
- ☐ Cultural adaption
- ☐ Consulting with ethnic minority groups
- ☐ We don't carry out any of these checks
- ☐ Not applicable, we don't translate our study documents
- ☐ Don't know
- ☐ Other (please specify)

25. How is interpretation provided in most of your trials *(please select all that apply)*? *

- ☐ Face-to face
- ☐ Over the telephone
- ☐ Online
- ☐ Don't know

- [ ] Not applicable, we don't provide interpretation

26. How do you calculate how much extra time a routine trial consultation will take with an interpreter? *

- ◯ Multiply the total time by 2
- ◯ Multiply the total time by 2.5
- ◯ We don’t add on any extra time
- ◯ Don’t know
- ◯ Not applicable, we don't provide interpretation
- ◯ Other (please specify)

27. In your trials, are relatives/ carers/ friends permitted to interpret for the patient during the recruitment consultation? *

- ◯ Yes
- ◯ No
- ◯ Depends on the trial
- ◯ Don't know

28. *How does this work and is this alongside or instead of using a professional interpreter?* *

SECTION 3: Management of Translation and Interpreting services

Please consider ALL trials within your CTU which are currently active, i.e recently funded through to being in the closedown process

29. Which companies and/ or services do you use for interpretation and translation services *(please select all that apply)*? *

For-profit agencies (e.g Langauge Line, Cintra, The Big Word)

- [ ] Translation
- [ ] Interpretation

Non-profit agencies (e.g Clear Voice interpreting, The Other Perspective)

- [ ] Translation
- [ ] Interpretation

Individual Interpreters or translators

- [ ] Translation
- [ ] Interpretation

NHS in-house services

- [ ] Translation
- [ ] Interpretation

NHS using their own agency

- [ ] Translation
- [ ] Interpretation

Billingual healthcare workers

- [ ] Translation
- [ ] Interpretation

Billingual co-workers in your CTU or organisation

- [ ] Translation
- [ ] Interpretation

AI online service/ platform

- [ ] Translation
- [ ] Interpretation

Not applicable, we don't use these services

- [ ] Translation
- [ ] Interpretation

30. If you use For-profit agencies or Non-profit agencies, please can you tell us which ones and what you use them for specifically?

31. How do you decide which translation and interpretation company to use *(please select all that apply)*? *

- [ ] We use those that have the highest standards, and we carry out checks beforehand
- [ ] We use those that we worked with before and had a good experience with, but we don't carry out any checking of standards
- [ ] We select only those with ISO standards
- [ ] We select the cheapest
- [ ] Other (please specify)

32. Do you use the same services for every trial? *

- ◯ Yes
- ◯ No
- ◯ Sometimes

33. Why do you choose to use the same services for each trial?

34. Why do you not or not always use the same services for each trial?

35. Does your CTU hold an account with the services? *

- ◯ Yes
- ◯ No

36. Do you carry out any checks on the services? *

- ◯ Yes
- ◯ No
- ◯ No, but plan to

37. If no, please tell us why not *(select all that apply)*? *

- ☐ Don’t have enough time
- ☐ Don’t know how to do this
- ☐ I don’t think it is required
- ☐ Other (please specify)

38. If yes, please tell us which checks you carry out *(select all that apply)* *

- ☐ Check qualifications of staff who will be carrying out the work are qualified at level 6 in a Diploma in Public Service Interpretation (DPSI)
- ☐ Request to see QA/ISO standards
- ☐ Unsure
- ☐ Other (please specify)

39. If no, but we plan to, please tell us which checks you plan to carry out *(select all that apply)* *

- [ ] Check qualifications of staff who will be carrying out the work are qualified at level 6 in a Diploma in Public Service Interpretation (DPSI)
- [ ] Request to see QA/ISO standards
- [ ] Unsure
- [ ] Other (please specify)

40. How often do you carry out these checks? *

41. How do you pay for translation and interpretation services in your trials *(please select all that apply)*? *

- [ ] We have an account with the service provider
- [ ] We cost in an upper limit for each trial for these services
- [ ] We set up an agreement with the services with each individual trial
- [ ] We pay the NHS sites for these services ad-hoc
- [ ] Unsure
- [ ] Other (please specify)

42. Do you provide training to NHS site staff (or equivalent recruiting staff) for support with translation and interpretation services? *

- ◯ Yes
- ◯ No
- ◯ Don't know

43. If yes, please can you add further details about the training provided below *

44. What do you think are the biggest barriers to using translating and interpretation services in trials research? *

45. Please select your role *

- [ ] Director
- [ ] Operations Lead
- [ ] EDI Lead
- [ ] Trial Manager/ Trial Coordinator
- [ ] Data Management role
- [ ] Other (please specify)

46. Please enter your name if you would like to be entered into the £50 Amazon prize draw

47. Please enter your e-mail address if you would like to be entered into the £50 amazon prize draw

48. Please let us know if you are happy to be contacted about the following:

- [ ] I would be happy to be contacted to take part in an interview and understand that I can change my mind later
- [ ] I would be willing to share the CTU's EDI strategy and/or any EDI related SOPs
- [ ] I would like a copy of the summary findings

Note: you will need to leave us your e-mail address above in order for us to contact you about the above!

Many thanks for taking the time to complete the INVITE study survey.

If you would like to provide any feedback, please e-mail Dr Kirsty Roberts at kirsty.roberts@bristol.ac.uk.