

Inclusive Health & Social Care Research

Guidance Toolkit for including people with language needs

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How to use this Toolkit

This guidance sets out practical steps to ensure inclusion is planned across the entire research lifecycle, rather than being treated as an add-on. It is designed to be used flexibly, with sections accessed as needed depending on the stage of a project, not necessarily read in a linear way. Key messages are repeated to ensure that important considerations are reinforced across different stages of the research process.

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1. Introduction

This guidance supports health and social care researchers to include people who require bilingual support to understand and express themselves fully in English.

Inclusive research:

- improves the relevance and quality of findings
- reduces health inequalities
- is increasingly required by funders such as NIHR, UKRI, and Wellcome

In Sussex, approximately **4% of residents have a first or preferred language other than English**, with higher levels of linguistic diversity in urban centres; Crawley, Brighton & Hove, Hastings and the West Sussex coastal towns.

Language needs are often not adequately considered in research design, leading to the exclusion of important perspectives, gaps in evidence and ultimately services and interventions that do not fully meet the needs of diverse communities, reinforcing existing health inequalities.

This toolkit was developed through a collaborative, co-production approach using a series of iterative workshops. Contributors included researchers from academic, clinical and applied disciplines, alongside Bilingual Community Researchers and VCSE organisations. Their real-world insights into challenges and effective practice, combined with a supporting literature review, have informed the structure and content of this guidance.

Quotes used throughout are drawn directly from the workshops, and bilingual community research undertaken by **Sussex Interpreting Services**, which reflect the professional and lived experience of those involved in research and community engagement.

“Just because someone is not able to express themselves well in English...doesn’t mean they can’t make a meaningful contribution... people come with different forms of knowledge and experiences that can enhance research.”

VCSE Community Engagement Manager

“It has long been common to see to an exclusion criteria about participants requiring English which obviously compromises the depth and breadth of the data.”

Academic Researcher

“I don’t have any experience participating in Health & Social Care research, but I would be keen to take part if there were no language barriers during the process”

Arabic Speaking Research Participant



2. Key principles for including people with language needs

Plan early

- Language support must be considered from the design stage, not added later.

Budget for inclusion

- Inclusive research requires time, funding, and specialist input

Consider the full participant journey

- Ensure communication is supported at every stage, not just during data collection.

Work with communities

- Inclusive research is not just about translating documents; it requires relationships, trust, and engagement.

Language is only one barrier

- Culture, knowledge, information, power and trauma can also form barriers to participation.

Use a combination of approaches

- Most studies will require a mix of translation, interpreting and other bilingual support.

Build trust and explain purpose clearly

- People are more likely to participate if they understand why the research matters and how it may benefit them or their community.

Use accessible communication

- Written translation alone is often not enough; consider video, audio, or face-to-face explanation.

Take an asset-based approach

- Do not assume lower English proficiency reflects lower capability or potential.
- Respect lived experience and community expertise.

“Participants had previously felt silenced or excluded from research due to language barriers, cultural stigma, and a lack of trust in institutional systems.”

Bilingual Community Researcher



“Everything had to be translated... even ‘press this button’... if you’re going to actively recruit, you have to look at every single part.”

Clinical Researcher (maternity)



“In some communities... it’s not acceptable for a man to interview a woman... this can make the difference between people accepting or turning down interviews.”

Bilingual Community Researcher



3. Understanding who to involve

Before designing your study, identify which language communities are relevant.

Key considerations

- Does your study focus on a specific condition, age group, location?
- Which languages are most commonly spoken within that group locally?
- Are there different dialects, literacy or cultural considerations?

Understand how communities engage

- Where do people meet?
- Which digital platforms do they use (e.g. WhatsApp, Telegram, Facebook)?
- What communication formats work best?

Engage early with:

- local VCSE organisations
- community groups and leaders
- places of worship
- existing local networks

Consider wider barriers in addition to language

- trust and past experiences
- cultural expectations
- stigma around topics
- digital access and skills
- health literacy
- socio-economic factors and financial stability

“You have to go to people in their communities... create an environment where they feel comfortable... culturally appropriate.”

Bilingual Community Researcher

”

“It’s not just about language... it’s about where you build trust and how you access populations.”

NIHR Research Network Lead

”



4. The Research Cycle

Inclusive practice should be considered at every stage of the research lifecycle.



4.1. Identifying & Prioritising

Identify and prioritise language groups early using local data and community insight.

Key questions

- Who is most affected by this issue?
- Which language groups are under-represented?
- Which languages are most commonly spoken locally?
- What additional barriers might these groups face in participating?

Key actions

- Identify relevant language communities
- Review local data (e.g. interpreting data, community insight)
- Consult national datasets where needed (e.g. census data)
- Engage early with VCSE organisations or community representatives

Good practice

- Use multiple data sources to inform decisions
- Prioritise languages based on demonstrated need and likely engagement
- Validate assumptions with community insight before committing resources

Sources of language data

- Interpreting and translation service data
- GP practice patient language records
- Local authority reports (e.g. JSNAs, EDI profiles)
- Public health team data and needs assessments
- School census / English as an Additional Language (EAL) data
- VCSE organisations and community groups
- UK Census (ONS) language and English proficiency data
- ONS population and migration datasets
- Previous research studies and local insight reports



“We translated into multiple languages at the start ... but only a couple were used... it becomes an expensive thing.”

Clinical Trial Manager

4.2. Designing & Planning

Plan language support from the outset to ensure feasible, consistent and inclusive research.

Key questions

- How will participants take part, and what language support is required?
- What ethical or methodological constraints need to be addressed?
- What resources (time, budget, staffing) are required for inclusion?

Key actions

- Build inclusion into study design and funding application from the outset
- Decide on appropriate language support methods
- Consult with community representatives or bilingual researchers
- Cost all potential language support; (translation, interpreting, community researchers, accessible formats, transcription software)
- Ensure enough time is built in for language support

Good practice

- Finalise English materials before translation
- Allow sufficient time for quality assurance such as proofreading, back translation, interview transcription
- Build flexibility into timelines and budgets



4.2. Designing & Planning

CASE STUDY

Plan for inclusion from the outset

Scenario

A primary care research team was designing a study to evaluate a diabetes intervention across several GP practices.

What the researchers did

- used local interpreting data to identify key language groups
- built in bilingual support for community outreach to explain the study and gauge interest
- translated Patient Information Leaflet, consent forms and outcome measures only in languages with expressed interest
- made contingencies in timelines and budget for translation and interpreting as needed

Key learning

Including people with language needs requires early methodological planning, not just additional resources.

“Language support needs to be a priority in the planning and budgeting stages... otherwise it becomes a real barrier.”

*Doctoral Researcher
(diabetes)*



“Including the community at design stage... is not as easy as it sounds... there’s no funding yet and people should be paid.”

*Project manager
(global health research)*



CASE STUDY

Inclusion introduced too late in the research process

Scenario

A multi-site NHS study began recruitment without planning for participants with language needs. Language support was introduced later in response to low diversity.

What happened

- inconsistent use of translation and interpreting across sites
- variation in participant experience
- difficulties comparing data across groups

Key learning

Early, structured planning of language support is critical to maintain rigour and data consistency.



“We sometimes only have 72 hours to recruit... if they don’t speak English, it just isn’t possible.”

*Clinical Research Nurse
(cancer)*

4.3. Recruitment & Engagement

Actively engage communities using trusted networks and communicate in preferred languages.

Key questions

- How will people hear about the research?
- Is information accessible in their preferred language and format?
- Do participants trust the organisation or messenger?
- Can participants easily respond or sign up?

Key actions

- Develop recruitment strategies using trusted community networks
- Provide information in appropriate languages and formats
- Ensure clear, accessible routes for expressing interest or signing up

Good practice

- Work through VCSE organisations and community leaders
- Use a mix of formats (written, audio, video, face-to-face)
- Ensure instructions and processes are fully accessible (not just materials)
- Support participants throughout the recruitment process



আপনার মাতৃত্বকালীন
এবং নবজাতকের
যত্নের অভিজ্ঞতা শেয়ার
করতে আমাদের সাথে
যোগ দিন



আমরা এদের মতামত শুনতে চাই...

- কৃষ্ণাঙ্গ, বাদামী এবং সংখ্যালঘু জাতিগত মহিলা।
- যাদের প্রথম বা পছন্দের ভাষা ইংরেজি নয়।
বাংলা ভাষায় সহায়তা পাওয়া যাবে।



24শে নভেম্বর 2025

স্থান - সেন্ট্রাল ব্রাইটন

সকাল 10টা থেকে দুপুর 2টা পর্যন্ত





4.3. Recruitment & Engagement

CASE STUDY

Recruitment through trusted community networks

Scenario

A study working with migrant communities in Sussex partnered with bilingual community researchers (BCRs) linked to a local VCSE organisation.

What the bilingual community researchers did

- used their community knowledge to display/distribute translated posters in shops, restaurants and places of worship frequented by the target community, and on commonly used social media platforms
- visited community groups and explained the study in participants' preferred language
- directly supported registration and ensured consent was understood

Key learning

Working through trusted community relationships is often more effective than standard recruitment methods.

“Linguist involvement was invaluable to reach participants who found it difficult to access through other channels. It was helpful they already knew each other; this supported rapport-building.”

*Research Lead
(digital inclusion)*



“Families from refugee backgrounds told us that there’s no way they’d respond to an information sheet or newsletters ... they’d need additional scaffolding support”

*PPIE Specialist
(children & families)*



CASE STUDY

Translation alone did not increase participation

Scenario

A research team translated a health survey into several languages and made it available online

What happened

- very low response rates from target communities
- instructions and surrounding content remained in English
- completing the survey required printing out and then posting the survey
- no promotion through community organisations

Key learning

Translation alone is rarely sufficient. Recruitment requires accessible communication, active engagement, and trusted routes into communities.



“We took time to build confidence during recruitment, combining translated information with outreach and phone calls to encourage involvement.”

*Bilingual Community
Researcher*

4.4. Data Collection

Use culturally appropriate methods and comprehensive language support to enable meaningful participation.

Key questions

- What type of language support do participants need?
- Are materials and methods accessible for different literacy levels?
- Are researchers equipped to work effectively with interpreters or Bilingual Community Researchers?
- Have researchers understood and considered additional culture, digital, socio-economic barriers?

Key actions

- Select appropriate data collection methods (e.g. translated surveys, interpreted interviews)
- Plan for validation of translated materials and first language transcripts
- Ensure accessibility of format, setting and participation requirements

Good practice

- Brief interpreters and develop shared terminology
- Allow additional time for interpreted sessions
- Match approach to participant preference and context
- Ensure consistency in translation and data collection processes across participants



4.4 Data Collection

CASE STUDY

Structured interpreting supported rigorous data collection

Scenario

A clinical study included participants with language needs in structured interviews assessing patient experience.

What the researchers did

- used professional interpreters for interviews
- briefed interpreters in advance and developed a shared glossary
- extended interview times and trained researchers in working with interpreters

What happened

- consistent data collection across participants
- improved quality and comparability of responses

Key learning

Interpreting can be integrated into research in a way that maintains rigour, consistency, and inclusion.

“At first I was nervous, but, with the help of the interpreter I found it much easier than expected.”

*Spanish Speaking
Research Participant*

”

“The only person who truly understands everything is the interpreter, they can’t be treated as automatons, the process must be much more relational.”

*PPIE Specialist
(children & families)*

”

CASE STUDY

Inconsistent translation can compromise data validity

Scenario

- survey questions were translated without clear instructions about concepts
- no verification methods such as proofreading or back translation were used

What happened

- surveys were translated differently across language groups
- no standardised wording or approach
- data became difficult to compare across language groups

Key learning

Unstructured translation introduces measurement bias

“This is a safe space and it’s good to talk about these things and understand more but I wouldn’t bring this up in other environments where our community meet like the church or mosque.”

*Bengali Speaking
Research Participant*

”

4.5 Dissemination

Share findings in accessible ways to build trust and support future engagement.

Key questions

- How will findings be shared with participants and communities?
- What formats and channels are most appropriate?
- How can dissemination support trust and future engagement?

Key actions

- Develop accessible outputs e.g. translated summaries, audio/video, community presentations, posters and zines
- Tailor level of detail and format to audience needs
- Share findings through appropriate community channels

Good practice

- Involve participants or community representatives in dissemination
- Use clear, visual, and concise formats where possible
- Ensure outputs are accessible and culturally appropriate
- Use dissemination to build ongoing relationships

CASE STUDY Community-led dissemination

Scenario

A study built in time for participants to create outcome summaries for their communities

What happened

- Participants met to discuss the key outcomes for them from the study
- They designed posters to present the findings
- The researchers produced English and community language versions
- The results were shared in community groups and venue
- There was increased understanding and a commitment to future engagement

Key learning

Accessible dissemination builds trust and long-term participation.

***“A simple leaflet...
clear, visual, concise...
was much more
user-friendly than a
full report.”***

*Bilingual Community
Researcher*

***“Participation
shouldn’t feel
extractive... people
want to know how
their input made a
difference.”***

*Research Fellow at
the University of Sussex*

***“We felt valuable that
we took part in this
project and created
posters to show what
we have done”***

*Chinese Speaking
Research Participant*

4.6 Evaluation & Feedback

Assess how well language needs were met to improve future inclusion.

Key questions

- Who took part, who did not -and why?
- How accessible and inclusive was the research process?
- What can be improved for future studies?

Key actions

- Collect feedback from participants on their experience; particularly accessibility and communication
- Monitor engagement and participation across different groups
- Review effectiveness of language support approaches

Good practice

- Build feedback collection into the study design
- Be transparent about outcomes and limitations
- Communicate clearly about timelines and next steps
- Use learning to inform future research and engagement



問題 1：你對自己與他人社交的滿意程度如何？

1	2	3	4	5
我非常不滿意	我不滿意	有時我不滿意	我算是滿意	我非常滿意

問題 2：你與不講相同語言的人社交的頻率如何？

1	2	3	4	5
從不	很少	有時候	經常	非常頻繁

問題 3：你多常參加社交活動或從事興趣愛好？

1	2	3	4	5
從不	少於一星期一次	每星期一次	一星期幾次	每天

問題 4：你參加新社交活動的可能性有多大？

1	2	3	4	5
非常不可能	不可能	中立	可能	非常可能

問題 5：你對可使用的服務及活動了解程度如何？（例如：社交活動、社區活動、課程、興趣班等）

1	2	3	4	5
我不知道在哪裡找到相關資訊	我對當地的服務了解不多	我對當地的服務了解一點	我擁有大部分所需的資訊	我擁有所有所需的資訊

“Before getting involved in this project, I thought research was a big thing, at a very high level, but now I know it is quite easy to get involved”

Turkish Speaking Research Participant

“I anticipated it would be a fantastic experience, but I couldn’t foresee the significant impact Community Research would have on participants, who truly valued being included in such research”

Bilingual Community Researcher

5. Choosing the Right Approach

5.1. Translation

“The accurate written transmission of meaning from one language to another, which is easily understood by the reader”

When to use

- When participants need to read or complete written materials in their preferred language e.g. consent forms, participant information leaflets, surveys, recruitment materials, outcome summaries
- When consistent wording is required across participants

Key considerations

- Use professional translators working into their primary language
- Use plain, accessible English
- Consider dialect, cultural differences and local context
- Plan for quality assurance, such as proofreading or back-translation
- Consider literacy levels and whether alternative formats (audio, video, visual) are needed
- Always finalise English materials before translation where possible

Good practice

- Provide translators with clear context, purpose, format and audience
- Build terminology glossaries to ensure consistency across materials and over time
- Allow time for queries and clarification from translators
- Use community validation to strengthen accuracy and usability
- Ensure final proofreading after formatting or design changes

Common pitfalls

- Translating into multiple languages without understanding actual need
- Translating materials but not recruitment information or instructions
- Assuming translated surveys will be completed without additional support
- Using AI or automated translation without quality checking
- Translating draft materials leading to inconsistency and errors
- Over-relying on written translation where literacy or engagement is a barrier

For a translation quote contact:
projects@sussexinterpreting.org.uk

“If they just received an invite in their language they may not have responded because they would be unsure or worried about being tricked, but, because they knew and trusted us they were willing to take part.”

Bilingual Community Researcher



5.2 Interpreting

“The accurate oral transmission of meaning from one language to another, which is easily understood by the listener”

When to use

- When participation involves spoken communication e.g. interviews, focus groups, consultations
- When participants prefer or need to speak in their own language
- When topics are complex, sensitive or require detailed responses

Key considerations

- Use professional interpreters, not family or friends
- Match language, dialect, and cultural background
- Choose the most appropriate mode and model of interpreting e.g. consecutive, summary or simultaneous, face to face, video or telephone
- Allow additional time (typically double) for interpreted sessions
- Plan for appropriate environment, confidentiality and minimal interruptions
- Brief interpreters in a pre-session on purpose and context of the session, terminology and concepts, and discuss any potential sensitivities or risks
- Ensure researchers understand the interpreter’s role as an accurate, impartial, confidential communication tool

Good practice

- Speak directly to the participant, not the interpreter
- Use short, clear sentences, with pauses for interpreting
- Avoid jargon, abbreviations and complex language
- Allow interpreters to intervene or clarify where needed
- Check understanding regularly throughout the session
- Recognise the cognitive and emotional demands on interpreters and provide breaks

Common pitfalls

- Using family members, friends or informal interpreters
- Assuming the interpreter will lead or manage the interaction
- Ignoring cultural or interpersonal preferences e.g. gender, age, religion, political context
- Underestimating the time and coordination required for interpreted sessions

**For an interpreting quote contact:
projects@sussexinterpreting.org.uk**

“Although they said they didn’t need an interpreter... it was quite a challenge... we never really knew whether they were fully able to engage and understand.”

*Social Science Researcher
(family research)*

5.3 Bilingual Community Researchers (BCRs)

“An individual with lived experience of the target demographic who acts as a crucial link between traditional researchers and underrepresented or marginalised communities ”

When to use

- When trust, engagement and access are key challenges
- When working with communities less familiar with research
- When participants face language, literacy, culture and/or confidence barriers

Key considerations

- BCRs combine language skills, cultural and community insight with lived experience
- They can support throughout the research cycle
- Provide clear roles, objectives and expectations, including how findings will be used
- Plan for training, safeguarding and ongoing support
- Consider practical and accessibility needs e.g. time, travel, digital access, payment
- Plan for transcription, translation and analysis of multilingual data
- Ensure appropriate governance, ethics and confidentiality processes

Good practice

- Involve BCRs early in design and planning
- Work with BCRs to shape research questions, materials and recruitment approaches
- Use BCRs to:
 - recruit through trusted networks
 - explain research and consent clearly
 - support or conduct data collection
- Provide training, mentoring and regular check-ins
- Provide debrief and emotional support, particularly for sensitive topics
- Combine BCRs with translation and/or interpreting where appropriate

Common pitfalls

- Unclear roles, expectations or lack of training
- Assuming language skills alone are sufficient
- Insufficient support, supervision or safeguarding
- Over-reliance on BCRs without other approaches
- Poor planning for multilingual data handling and analysis
- Using BCRs in highly standardised designs without adaptation

For a BCR quote contact:

projects@sussexinterpreting.org.uk

“It was great to be able to speak out through the support of a bilingual researcher since we have felt silenced by the system due to culture and language barriers.”

Portuguese Speaking Research Participant



6. Further Support

Language service providers (such as **Sussex Interpreting Services**) can support:

- identifying relevant language communities
- advising on engagement approaches
- providing interpreting and translation
- supporting recruitment and dissemination

Engaging specialist support early will improve both quality and inclusivity.

