Language Diversity in Research - Resources & Tips

Resources and best practices to overcome known language barriers in research at BMC

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Agenda

- **Introduction/Background**
  - Our commitment to inclusive research values
  - LEP Demographics at BMC
  - Known Language Barriers in Research & FDA Guidance

- **Language Diversity in Research**
  - Existing Translation Vendor Services & BMC Interpreter Services Workflow
  - Resources & Best Practices to Overcome Known Barriers
    - Negotiating with Sponsors for Translated Materials and appropriate funding to support LEP recruitment
    - Planning for translated materials during IRB approval process
    - Tips for working effectively with Interpreters and LEP patients

- **What's Next? NEW Engaging Patients with Limited English Proficiency in Research – SOP**
  - SOP Objectives
  - Method to Develop SOP
  - Timeline
**BMC is at a pivotal point in our research journey, with much momentum**

- Advancing research in service of our commitment to excellent care and health equity
- Leading the country in rigorous, interdisciplinary research that addresses our patient’s toughest challenges
- Partnering with patients in a highly ethical way
- Expanding clinical trials and partnerships with industry/life sciences companies are a key part of our core strategy

**BMC believes the opportunity to participate in research is an equity issue**

How we approach research sets us apart
BMC SUPPORTS RESEARCH INFRASTRUCTURE GROWTH AS PART OF THE CLINICAL CARE MODEL

Hiring of 1st Chief Scientific Officer
Building of Clinical Research Unit
Rewriting healthcare marketing campaign includes research
Investing in Center for Clinical Research Advancement

COMMUNITY INNOVATION HUB: CENTERED AND CATALYZED BY THOSE WE SERVE

Community Innovation Hub: collectively enhance human health through trust building, research, and discovery

Identify community's needs & areas of curiosity

Physical space in Nubian Square bringing together community and researchers
Virtual collaboration platform to foster scalable collaboration methods
Develop Symposium: Innovative Research Strategies for Achieve Health Equity
Co-create research questions, study designs, and build partnerships
Guide BMC research portfolio growth focus areas and clinician/patient needs for innovative care
Co-design tool to inform community of research opportunities, recruitment, and research results reporting
Language justice inclusive practices

Workforce development catalyzer

Research pipeline programs for under-represented minorities to obtain training in research professional staffing positions, PI roles, introductions to science for high school and college students
Research Ambassador training series and outreach program
Community member trainings: research design, evaluation methods, grant writing, financial management
DIVERSITY IN RESEARCH WORKFORCE

“My ABN Fellowship at BMC has been a thrilling experience. I’ve learned software systems, human subjects research fundamentals, and project management training. But more importantly, I’ve built relationships with professionals and experts in the healthcare field.”

-Cissy Ayebi, 2022 Fellow, now a BMC Clinical Research Coordinator in Infectious Diseases

- Value the individual- autonomy, trust
- Retention- saves money and increases efficiency
- Diverse language skills, add into job description to clarify roles and responsibilities
- Inclusion of cultural experiences
- Workforce development pipeline- ABN and Urban College of Boston partners

CYCLE OF INCLUSIVE RESEARCH

ADVANCE science with and for all people, improving health outcomes

ENGAGE diverse communities to develop trust and awareness around clinical research career pathways and economic mobility

DIVERSIFY research study participant enrollments through trustworthy approaches of next generation research staff

ACCEPT racially, linguistically, and culturally diverse early career research staff into immersive preceptorship

CULTIVATE culturally sensitive, quality driven mindsets to deliver exceptional, inclusive clinical research care delivery
YEARNLY TOTAL COMPLETED REQUESTS

YEARLY TOTAL COMPLETED REQUESTS

INTERPRETER BREAKDOWN BY MODALITY

BMC Volume by Modality
FY23 Avg Mo

Definitions

Phone
- Over the phone interpretation
- Only calls generated on a phone (e.g. dual handset, cell phone, Avaya), not through the Propio app

App
- Audio call OR video call generated through the Propio app (e.g. on BMC device, personal device, iPad on stand)

In person
- In-person BMC interpreter
KNOWN LANGUAGE BARRIERS IN RESEARCH


Make Trial Participation Less Burdensome for Participants
- Consider planned visit schedules and difficulties with access to site
- Fund and make participants aware of financial reimbursements for costs to participate in clinical trials (e.g., travel and lodging expenses).

Adopt Enrollment and Retention Practices that Enhance Inclusiveness
- More inclusive strategies for public outreach and education
- Community engagement through medical societies, focus groups, community advisory boards, disease registries, and community-based participatory research.
  - Include sites with a higher concentration of racial and ethnic minority patients and indigenous populations, as well as locations within the neighborhoods where these populations receive their healthcare.
  - Provide trial resources in multiple languages and multilingual research staff and/or interpreters to encourage the participation and retention of individuals with limited English comprehension.
  - Consider use of online/social media recruitment strategies to identify participants for whom a traditional referral center is not accessible.

Current Resources & Workflows
TRANSLATION & LOCALIZATION SERVICES
WHO CAN HELP AND HOW MUCH WILL IT COST?

ICF & RECRUITMENT MATERIAL TRANSLATION

CONTACT BMC’s Clinical Trial Office for Quotes: CTO@bmc.org
Translation & Localization Vendor: CYRACOM INTERNATIONAL, INC.
www.cyracom.com

- 300+ languages
- ISO-certified translation process
- Clear, concise, culturally relevant messaging (localization)

COST (PER WORD)

<table>
<thead>
<tr>
<th>Language</th>
<th>New Word</th>
<th>100% Match</th>
<th>Repeat Text</th>
<th>Fuzzy Match</th>
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<td>$0.03</td>
<td>$0.04</td>
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<tr>
<td>Haitian Creole</td>
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<tr>
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<td>$0.17</td>
<td>$0.04</td>
<td>$0.06</td>
<td>$0.11</td>
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<tr>
<td>Vietnamese</td>
<td>$0.18</td>
<td>$0.05</td>
<td>$0.06</td>
<td>$0.12</td>
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</tbody>
</table>

OTHER SERVICES

- $65 Translation Hourly Rate (Review, Glossary Translation)
- $65 Initial Source Language Glossary & Style Guide Creation
- $65 Post Translation DTP Format & QA Hourly Rate
- $65 Transcription and Voiceover Hourly Rate
- $65 Complex Multilingual DTP Hourly Rate
- $70 Graphics Localization
- $80 Multimedia Translation Integration
- $100 Project Minimum – All languages

SAMPLE TRANSLATION QUOTE

English to Haitian Creole

- Assent Script
- ICF
- Baseline Questionnaire
- Eligibility Screening Script – In Clinic Setting
- Eligibility Script – Response to Flyer
- Study Brochure
- Study Flyer

Total Cost: $1,795
STUDY SET-UP

1. Research teams are responsible for the interpreter costs and must build these costs into the funding/grant budget during study start-up.

2. Please complete the Research Interpreter Service Form so we can set your team up with Propio®, our phone vendor (form also found on CTO website).
   https://bmc.tfaforms.net/137

3. Study Teams will have their own direct access to interpreters and will be billed directly by the vendor. This will allow your research team to receive your own call data reports.

HOW TO INITIATE SERVICES

1. After completing the Research Interpreter Service Form, study teams will be issued a study code.

2. To request Interpreter Support, call (617) 414-5549 (option #4) or 75757 from a BMC phone.

3. Enter your study code when prompted for a “dept code”

4. Request appropriate language

10 Tips on Working with Multicultural Patient

PROPIO INFORMATION CARD & COST

Boston Medical Center

1. To access interpreter, dial: 75757 or (617) 414-5549 (option #4)

2. Enter study code

3. Select target language

4. Provide required information:
   Patient MRN

Complete language list at: LanguageCodes.info

<table>
<thead>
<tr>
<th>Top Language Auto Attendant</th>
<th>Spanish</th>
<th>Haitian Creole</th>
<th>Cape Verde Creole</th>
<th>All Other Languages</th>
</tr>
</thead>
<tbody>
<tr>
<td>Phone Interpretation</td>
<td>$0.55/min</td>
<td>Video Interpretation</td>
<td>$0.65/min</td>
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</table>

Telephonic Interpreting Services
BMC LANGUAGE ASSESSMENT FOR BILINGUAL PROVIDERS & STAFF

- Any clinical staff interested in becoming an approved bilingual provider (ABP) should send a request to DG-LanguageAssessments@bmc.org with the candidate’s name, department, ID number, language to be assessed, and title.
- For candidates that completed schooling abroad, we will waive the assessment test upon submission of their diploma.
- Once a language proficiency skills assessment request has been received, the ISD management team will:
  ✓ Send the candidate a self-assessment evaluation
  ✓ Set the candidate up to take the appropriate assessment, based on the self-assessment results
  ✓ Our vendor will send the candidate an email with the instructions on how and when to take the language proficiency skills assessment, which takes 30-40 minutes
  ✓ Send the results to the candidate with instructions on how to document in Epic and the difference between ABP and a qualified medical interpreter

If the candidate passes the assessment, he/she will be considered an Approved Bilingual Provider (ABP) at BMC. ABPs will be able to provide direct care to LEP patients in a language other than English without an interpreter but cannot act as interpreters for other colleagues.

Best Practices for Known Barriers
**INCLUSIVE BUDGET COSTING & NEGOTIATION PRACTICES**

**Standard Budgeting Steps:**

- Complete Medicare Coverage Analysis
- Covert MCA into Study Budget Template
- Complete site pricing based on research designated fees in MCA
- Coordinate services and fees with site ancillary departments (lab, pharmacy, etc.)
- Review Protocol and Request CRFs to incorporate study team effort
- Confirm full study team and recruitment plan to incorporate appropriate funding

**Inclusive Budgeting Practices:**

- Set expectations for inclusive values and required funding with sponsor early in the study start-up process
- Share BMC demographics and recruitment impact when LEP funding is provided
- Work with sponsors through a collaborative approach—align goals and commitments
- Translation of ICFs and recruitment materials into multiple languages as appropriate
- Create tiered pricing that reimburses at a higher rate for Limited English Proficient patients to account for staff effort
- Consider Community Engagement as part of recruitment planning
- Include appropriate patient stipends and reimbursement to remove financial barriers

**Coming Soon in the Spring!** CRN and CTO will team up on a Clinical Trial Budgeting Workshop to take a deeper dive into maximizing budget, sharing negotiation strategies and management of study revenue.

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**DECENTERING ENGLISH DURING THE IRB APPROVAL PROCESS**

**Decenter**- To shift from an established center or focus

**Decenter English** by challenging the assumption that English is the only language of knowledge production and dissemination

**Decenter English during the IRB Approval Process** by planning for known language barriers in research conduct that have the effect of prioritizing the enrollment of English proficient participants

**Examples of barriers:**

- Perceived administrative burden
- Potential availability of Interpreter Services
- Cost of translation services
- Study specific training and research instruments only validated for English proficient context
DECENTERING ENGLISH DURING THE IRB APPROVAL PROCESS

Relevant IRB Questions
- What populations is this study targeting for recruitment?
- How are participants recruited?
- What is the consent process?

Document Management
- Consent Forms
- Patient facing surveys, questionnaires, and/or study instructions
- Recruitment materials and/or study advertisements

Implications
- Targeted vs. Incidental Recruitment
- Vulnerable population protections
- Use of Interpreter Services

HRPP Policy Section 8.4.5 Informed Consent for Non-English Speaking Subjects
- Presented in language understandable to participant
- Written in a language understandable to the participant
- Targeted (expected to enroll): full translation of entire consent
- Incidental (unexpected to enroll): short form
**LIMITED ENGLISH PROFICIENCY - LEP**

**Targeted (expected to enroll) – Fully Translated Consent**

- Translation of IRB-approved English consent – submitted to IRB as amendment
- Translator qualification form submitted to IRB with translated full consent
- Conversation should take place in language understandable to participant - Interpreter
  - BMC services
  - Minors cannot serve as interpreter
- Translated consent form signed by participant and investigator

**Incidental (unanticipated to enroll) – Short Form**

- IRB will provide Short Form and Short Form Signature Page as part of approval process
- Short form + Short Form Signature Page + English narrative (which can be English consent)
  - Stapled together – Originals kept by investigator
  - Stapled together – Copies given to participant
- Witness must be present
  - If verbal translation is done by study team member – need an impartial witness
  - If impartial interpreter used – that person can serve as witness too
- Conversation should take place in language understandable to participant - Interpreter
  - BMC services
  - Minors cannot serve as interpreter
- Short form signed by participant, witness, investigator
- Short Form Signature Page signed by witness and investigator

**WORKING EFFECTIVELY WITH INTERPRETERS**

“We [Interpreter Services] strive to provide cultural competency as we communicate sensitive information to our diverse patient population. Language and culture are strong inseparable elements that define a patient's identity and health care beliefs and practices. Therefore, Interpreter Services has an important role as a cultural broker. A patient's visit, assisted by a medical interpreter, will allow for a clear flow of communication and will also provide an opportunity to discover the beliefs and customs that affect the delivery of culturally competent health care services.”

Best Practices During a Visit | Boston Medical Center Intranet (bmc.org)

**Types of Interpretation:**

- Consecutive
- Simultaneous
- Sight Translation

**Types of Language Work:**

- Translation
- Respeaking
- Captions
- Subtitles
- CART
  (Communication Access Realtime Translation)
- Dubbing
- Voiceover
- Audio description
- Image description
WORKING EFFECTIVELY WITH INTERPRETERS

The 10 and 10

1. Give background
2. Empower the interpreter
3. Address the patient
4. Don't keep secrets
5. Keep it brief
6. Keep it simple
7. Teach back
8. Confirm interpretation
9. Debrief
10. Ensure confidentiality

Research Training for Medical Interpreters

1. How the regulatory environment was shaped by past harms
2. Exposure to key clinical research terms
3. Techniques and strategies for promoting comprehension in the research context specifically

What’s Next?
WHAT’S NEXT? – NEW SOP: ENGAGING PATIENTS WITH LIMITED ENGLISH PROFICIENCY IN RESEARCH

SOP Objectives:

- Consolidate existing BMC resources that support language diversity in research
  - Translation resources (with solutions for “localization” of terminology to ensure accuracy/understanding in BMC catchment area)
  - Budgeting guidance to financially plan for and secure appropriate funding
  - Access to trained BMC medical interpreters who have participated in our Research training
- Guidance for the research community to work more effectively with our LEP patients and Medical Interpreters to achieve understanding during the consenting process and in all research related interactions with our LEP patients.
- Cultural Competency guidance to educate researchers about the vulnerability of our LEP patients, and the additional time and care needed to establish trustworthy dialogue in a setting where routine care and research related opportunities can be difficult for our patients to understand and navigate with language and trust barriers

Questions?