

# What is ACCORDS?

Adult and Child Center for Outcomes Research and Delivery Science

ACCORDS is a 'one-stop shop' for pragmatic research:

- A multi-disciplinary, collaborative research environment to catalyze innovative and impactful research
- Strong methodological cores and programs, led by national experts
- Consultations & team-building for grant proposals
- Mentorship, training & support for junior faculty
- Extensive educational offerings, both locally and nationally



# ACCORDS Upcoming Events – mark your calendars!

Fall – Spring series	<b>Emerging Topics in Digital Health &amp; Clinical Informatics</b>
Fall – Spring series	<b>Transforming and Advancing a Learning Health System: Multiple Perspectives for Mutual Gain</b>
Annual Workshop October 21 & 25	<b>Introduction to Qualitative Research Workshop</b> Registration open at <a href="https://medschool.cuanschutz.edu/accords">https://medschool.cuanschutz.edu/accords</a> Space still available for morning didactic sessions
Spring Workshop Dates TBD	<b>Dissemination &amp; Implementation Science for Researchers Workshop</b>
Spring Workshop Dates TBD	<b>*New* Pragmatic Research Planning Workshop</b>
Annual Conference June 4-5, 2025	<b>Colorado Pragmatic Research in Health Conference</b> Future of Pragmatic Research: Team Science to Enhance Innovation and Impact



# ACCORDS Guest Lecturer Speaker Series

September 23, 2024



**Presented by:**  
Flavia Bianchi, MSc, MES

## **Engagement By All, For All: Increasing Spanish-speaking Partner Engagement in Research Through Capacity Building**



# Engagement By All, For All: Increasing Spanish-speaking Partner Engagement in Research Through Capacity Building

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Flavia Bianchi MES, MSc.  
Program Officer, Science of Engagement  
September 23, 2024



# Presentation Outline

- What is the Patient-Centered Outcomes Research Institute (PCORI)?
- Partner Engagement and the Science of Engagement
- What is the *Research Fundamentals* package?
- Spanish Translation of the *Research Fundamentals* learning package
  - Objective, Target Audience
  - Process and Review

# Patient Centered Outcomes Research Institute (PCORI)



## | What is PCORI?

PCORI is an independent, nonprofit research organization that seeks to empower patients and other stakeholders with actionable information about their health and healthcare choices.

PCORI is committed to ensuring that patients and other healthcare stakeholders have a seat at the table throughout the research process – helping to prioritize research topics, design and conduct the studies, and share the results.

## Meaningful Engagement

- Patients are true partners in all aspects of research
- Stakeholders across the healthcare enterprise actively and meaningfully involved throughout research process
  - Development of research questions through to dissemination and uptake of findings





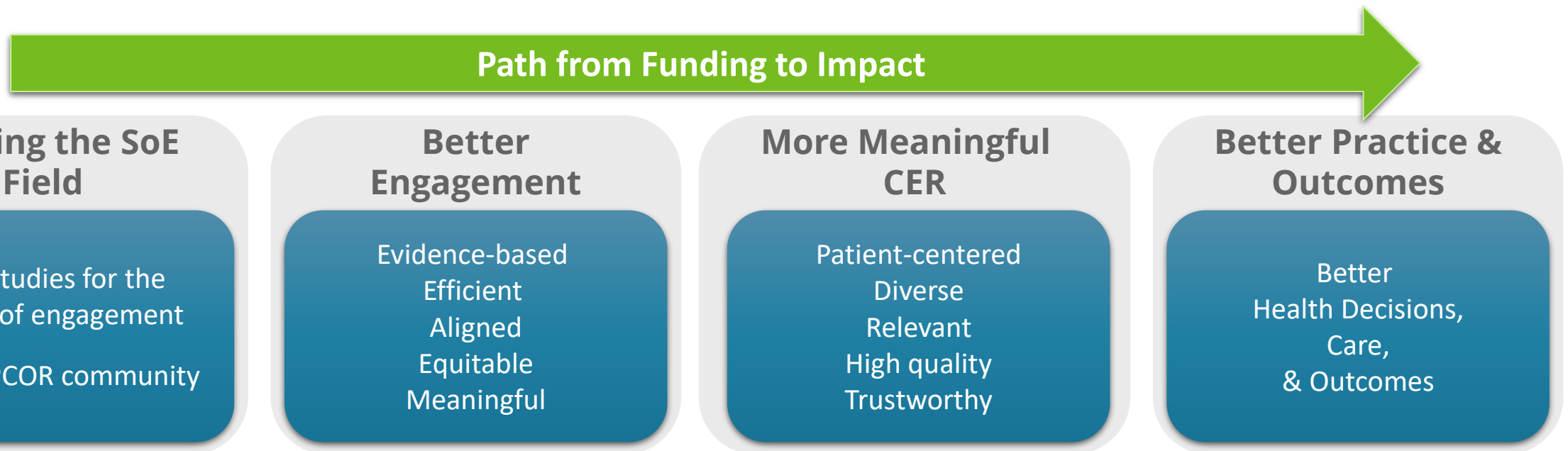
# The Science of Engagement



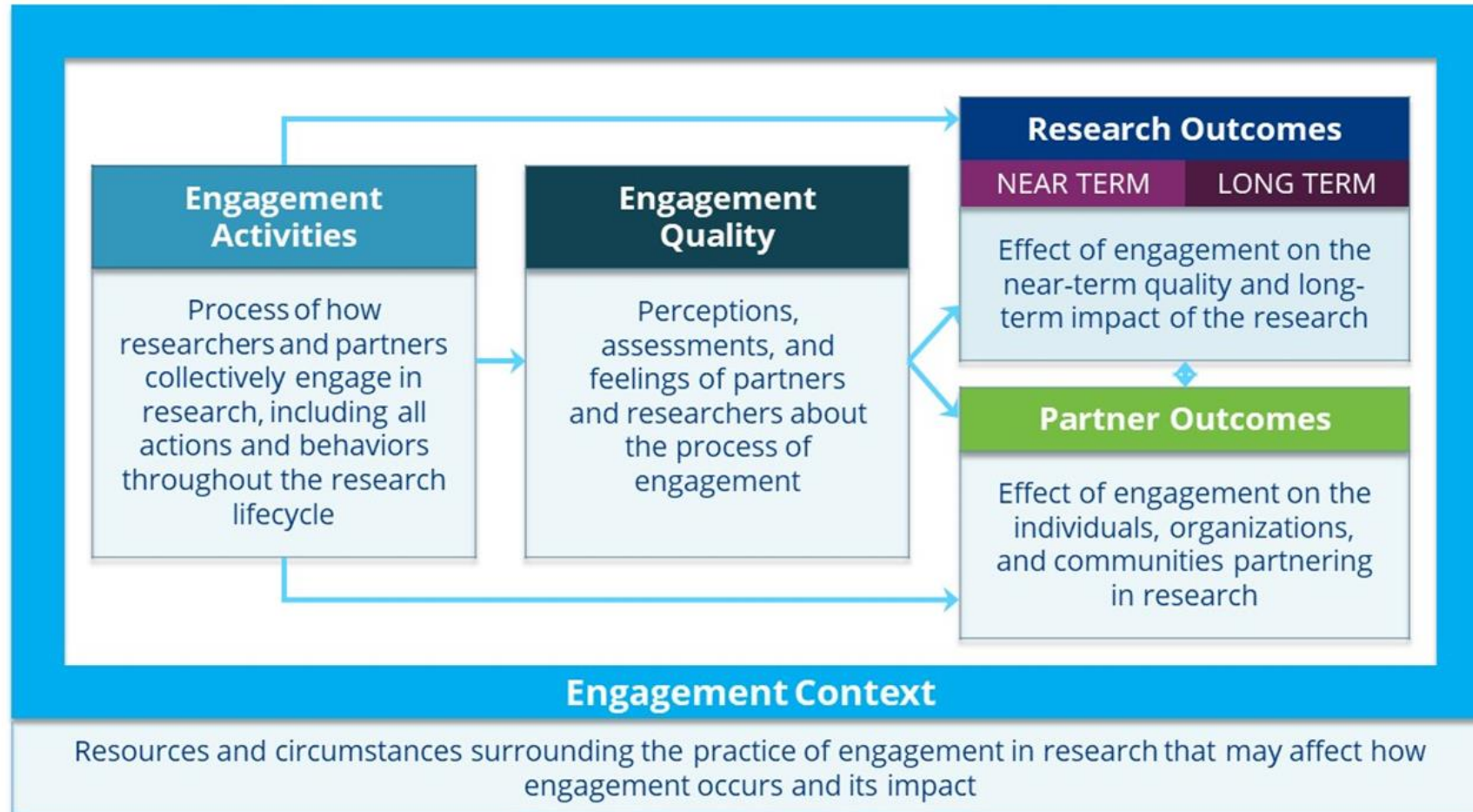
# Science of Engagement PFA

## Background & Purpose

- The objective of the Science of Engagement initiative is to build an actionable evidence base that clearly identifies the **methods and approaches that lead to effective engagement**.
- To accomplish this, the Science of Engagement initiative will also support projects to **develop and validate measures of engagement**.



## Engagement in Research: Theory of Action



# Engagement in Research

- Applicant resource describing PCORI's current priorities and conceptualization of engagement and engagement measures.
- <https://www.pcori.org/resources/measuring-what-matters-advancing-science-and-practice-engagement>

## Measuring What Matters for Advancing the Science and Practice of Engagement

Over the past decade PCORI has transformed how research is done by requiring engagement of patients and other partners to support research that is more rigorous, acceptable and relevant.<sup>1,2</sup> Although the practice and study of engagement have grown rapidly, there are few measurement tools available to manage engagement, identify best practices and equip research teams to optimize how they engage patients and other partners in research.<sup>3,4</sup>



PCORI has recently worked to identify and summarize aspects of engagement in health research that need to be measured to generate evidence for those who practice and study engagement. We identified 28 concepts about engagement in research and organized them into five domains to stimulate discussion and debate about an emerging framework to inform measurement tool development and use to guide and study engagement in health research.

Measurement tools, including questionnaires and surveys, are intended to collect information about engagement in standardized ways, which are reproducible and have been shown to capture what they claim to measure (known as reliability and validity in the scientific literature). These tools are crucial for collecting information about how engagement occurs within research teams and in what contexts, and what outcomes result. This information can support learning about engagement to serve various purposes (Box 1).

### What We Did

A key gap for measuring and studying engagement in research is the lack of a shared framework and language to describe the concepts in such a framework. We analyzed information from peer-reviewed publications; in-depth interviews with researchers, patients and other partners involved in engaged research; and public responses about existing and needed measurement tools (Box 2). We identified 28 concepts that begin to define important elements that, when measured or described, will support learning about engagement in health research (Table 1). We organized the measurement concepts into five common domains that build on and expand PCORI's conceptualization of how the context and process of engagement lead to outcomes for research and partners (Figure 1).<sup>5</sup> Measures aligned with each domain are essential for answering the full range of questions about the practice and impact of engagement in research (Box 3).



# Science of Engagement PFA

## Programmatic Priority Areas

- **Measuring Engagement (Category 1)**
  - The first priority and goal of this funding opportunity is to develop a set of reliable and valid measures that enables future comparative effectiveness research of engagement methods.
- **Developing and Testing Engagement Methods (Category 2)**
  - The second priority of this funding opportunity is to support research projects that evaluate the impact of different engagement methods on key processes and outcomes of engagement and research.

# Research Fundamentals



# *Research Fundamentals: Preparing You to Successfully Contribute to Research*



***Research Fundamentals*** is a comprehensive training package that helps people new to health research understand the language and logic of the health research process and be involved in patient-centered outcomes research.

## **The package also:**

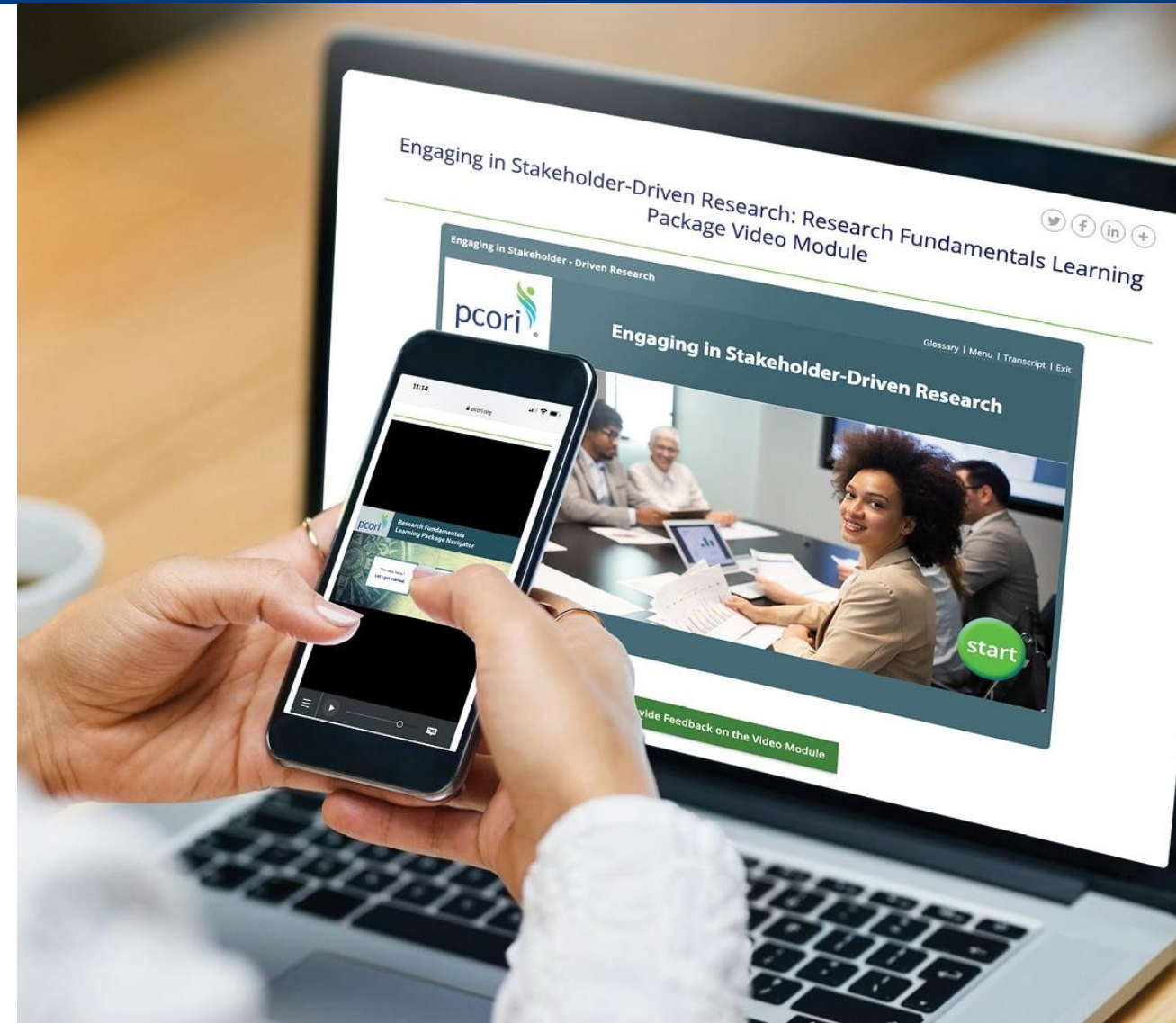
- Is free and available online 24/7
- Is easy to understand, written in plain language
- Consists of individual modules that can be viewed at an individual's pace
- Allows users to set their own path through the training using the Navigator tool, people can start and stop lessons as needed

# Research Fundamentals: Preparing stakeholders to contribute to research



The **Research Fundamentals** training package includes:

- Website landing page
- Seven self-paced modules
- Interactive PDF
- Static PDF





# Translation Process



# Translation: Intended Audience

The intended audience consists of **Spanish-speaking adults** in the United States, representing different:

- countries of origin or ethnicity,
- degrees of assimilation and acculturation,
- educational levels,
- literacy (including health literacy),
- experiences with the health care system in the U.S., and
- levels of knowledge and exposure to health research.

The audience also varies in age, gender identity, sexual orientation, and represents diverse families (two-parent homes, single parent homes, multi-generational homes, etc.).

# Translation: Process and Timeline



Three different TEP members were instructed to review specific text to **ensure the translated text met specific objectives** in the following key areas of:

- Comprehension
- Functionality
- Cultural relevance

In the next section, we summarize key decisions made in these three areas with specific examples.

# Summary of Key Decisions

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# Summary of Key Decisions - 1

Together, PCORI and the TEP made the **following decisions** when revising the Spanish translations:

## Comprehension

- Translations are in active voice
- Revised terms in favor of clear, concise and simple terms
  - Particularly important when introducing scientific terms (research methods, statistical terms, etc.)
- Decided to use the formal you (usted) for cultural competence and to be respectful of end users

# Summary of Key Decisions - 2

PCORI and the TEP made the **following decisions** when revising the Spanish translations:

## Functionality:

- If idiomatic or figurative language was used in English, used a translation that conveyed the message across and not simply translating a figure of speech that may not be clear in Spanish.
- Added prepositions, articles, nouns and pronouns as needed in Spanish for clarity, although they were often fine to omit in English.
- Revised the order of sentences so that in Spanish for clarity, the subject is first for example. In English, the reverse was often the case.

# Summary of Key Decisions - 3

Together, PCORI and the TEP made the **following decisions** when revising the Spanish translations:

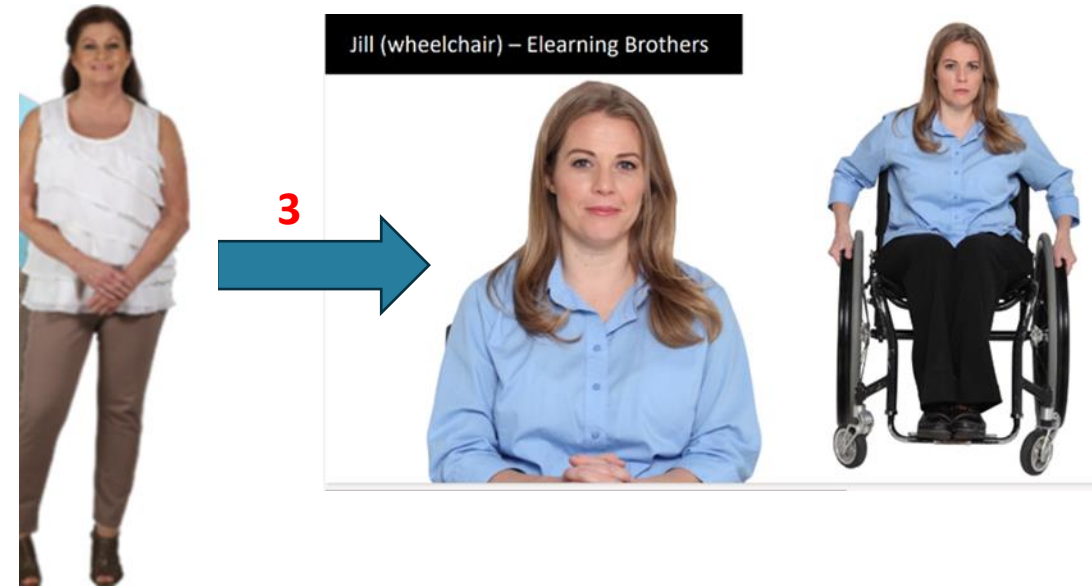
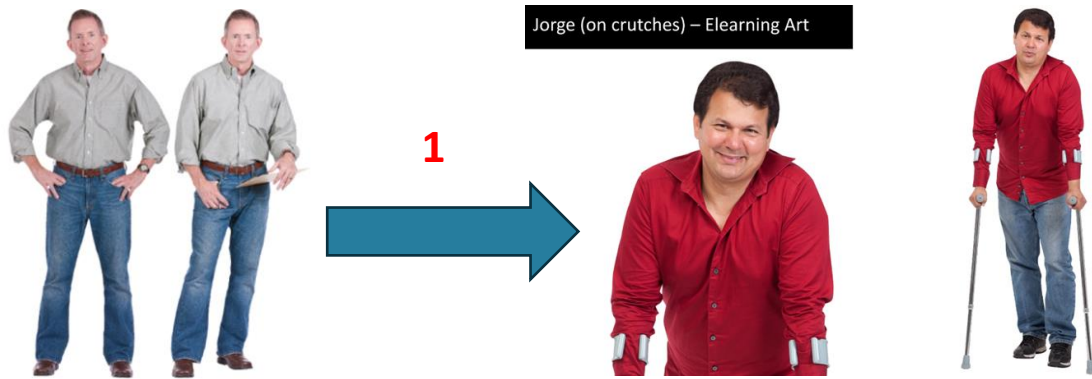
## Cultural relevance:

- Used terms that were more likely to be understood by Latinos living in the U.S.
- Used names that were culturally congruent.
- Visual character swaps for diverse phenotypes/faces and different able-bodied representation



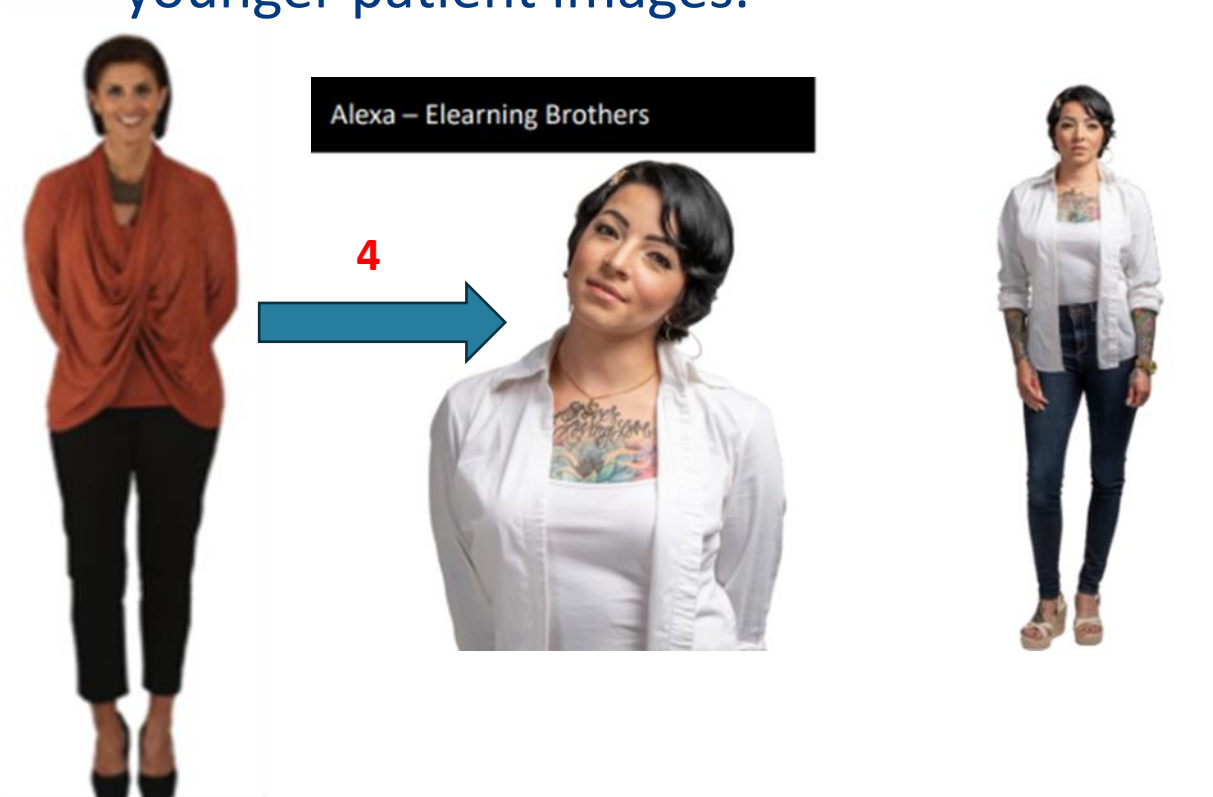
# Summary of Character Swaps

- Identified possible character swaps for the Spanish version.
  - Selected 5 changes on the basis of gender, diverse phenotypes, physical disability and younger patient images.



# Summary of Character Swaps (cont.)

- Identified possible character swaps for the Spanish version.
  - Selected 5 changes on the basis of gender, diverse phenotypes, physical disability and younger patient images.



# End-users' thoughts about the Translation of *Research Fundamentals*



“Reviewing the assigned content was a **rewarding experience** because it allowed me to see first-hand how PCORI’s efforts are **helping create an environment that is more inclusive** to the Spanish-speaking community. Seeing how **accessible and understandable information can increase participation in health research** was truly inspiring.” - *End-user reviewer*

“I think **the effort PCORI is making to include the Spanish-speaking community is excellent**. I think implementation of the modules in Spanish will **increase the participation of this population in health research studies**.” - *End-user reviewer*

# Research Fundamentals in Spanish: Now Online!

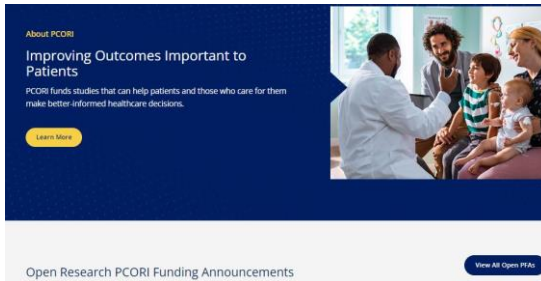


- [Fundamentos de la Investigación](#)
- [Research Fundamentals in Spanish](#)

- [Foundational Expectations](#)
- [Measuring What Matters](#)
- [Equity and Inclusion Guiding Engagement Principles](#)
- [Guide for Engaging with Research Partners about Data and Analysis](#)
- [Building Effective Multistakeholder Research Teams](#)
- [Research Fundamentals English](#)
- More can be found on PCORI's [Engagement Resources](#) page
  
- [\*\*Science of Engagement PFA\*\*](#)
- [Speaker Bureau](#)

- **Science of Engagement PFA**
- Schedule a call with Science of Engagement: SCIENCE OF ENGAGEMENT OFFICE HOURS SIGN UP FORM - CYCLE 3 2024 (smartsheet.com)
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# Where can I find help?



## Visit [pcori.org](https://www.pcori.org)

- Submission Instructions
- FAQs
- PCORI Online User Manuals
- Engagement Resources

## Schedule a Call with a Program Officer

- Schedule a call with Science of Engagement: [SCIENCE OF ENGAGEMENT OFFICE HOURS SIGN UP FORM - CYCLE 3 2024 \(smartsheet.com\)](#)
- Submit a request at [pcori.org/content/research-inquiry](https://www.pcori.org/content/research-inquiry)
- E-mail [sciencequestions@pcori.org](mailto:sciencequestions@pcori.org) (for CER studies)
- Email [ea@pcori.org](mailto:ea@pcori.org) (for Engagement Awards)

## Contact our Helpdesk

- E-mail [pfa@pcori.org](mailto:pfa@pcori.org)
- Call 202-627-1885 (administrative and technical inquiries)



# Questions?



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# ¡Muchas gracias!

