AAHRPP
Association for the Accreditation of Human Research Protection Programs, Inc.®

2025 AAHRPP Webinar Series

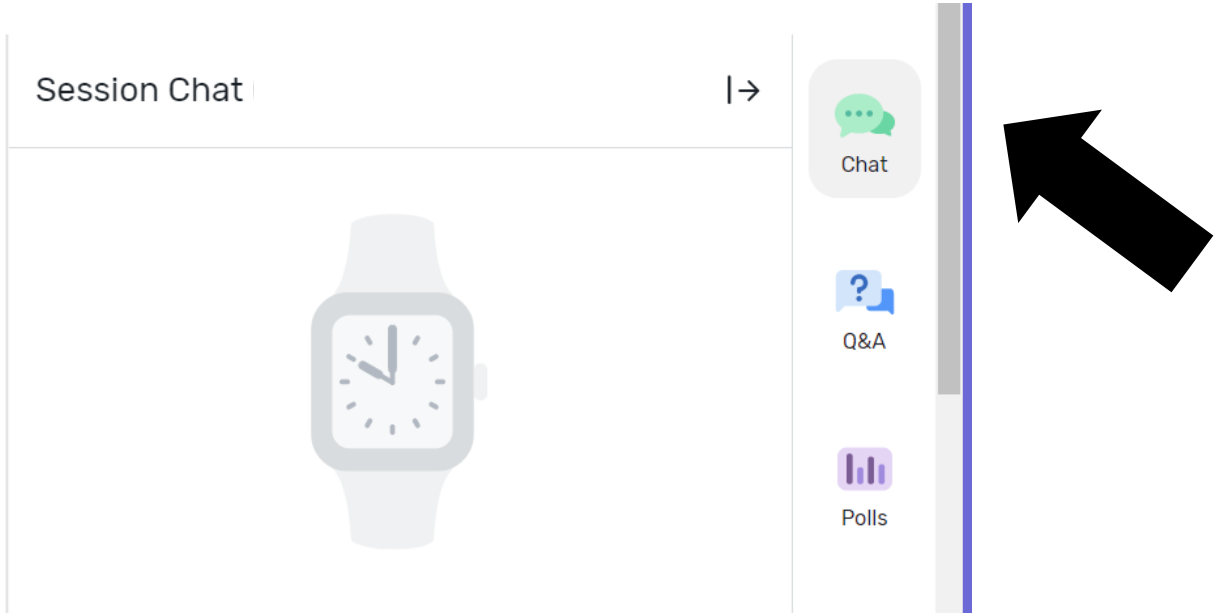
A 2025 "HRPP Innovations" Webinar:

Participant & Community Outreach and Collaboration: Innovative Practices by AAHRPP-Accredited Organizations

November 18, 2025; 1:00 pm – 2:30 pm ET

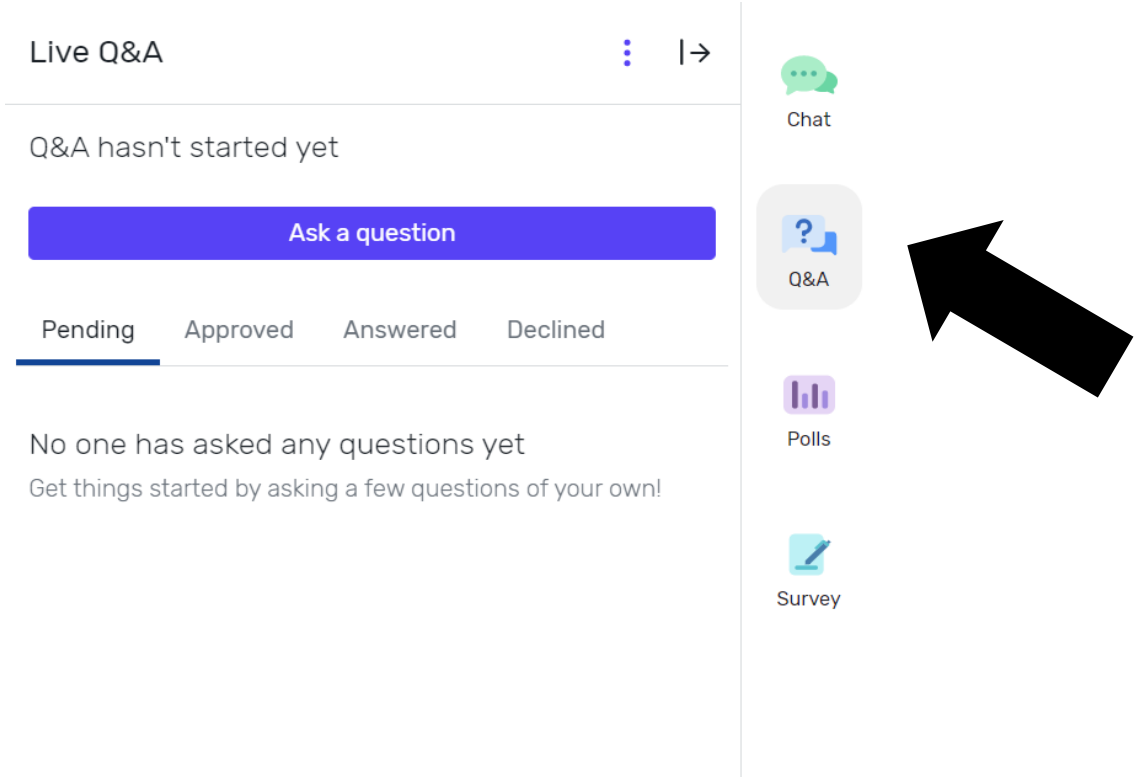
Chat Feature

To chat with your colleagues before and after the session, or if you have technical questions, use the “Chat” icon



Questions

To ask questions about the topic for the presenters, please use the “Q&A” icon:



AAHRPP
Association for the Accreditation of Human Research Protection Programs, Inc.®

Upcoming Webinars

Ask... AAHRPP®

Save the date for the remaining 2025 "Ask AAHRPP" webinar:

- December 9, 2025 – Responding to Council Review and Maintaining Accreditation

Visit Webinars (aahrpp.org) for more information and registration links

Visit AAHRPP's Annual Conference page for more information

AAHRPP
Association for the Accreditation of Human Research Protection Programs, Inc.®

Presenter Introductions

Adam Gleeson

Celerion, Inc.

AAHRPP

Association for the Accreditation
of Human Research Protection Programs, Inc.®

Francesca Gany

Memorial Sloan Kettering Cancer Center

AAHRPP

Association for the Accreditation
of Human Research Protection Programs, Inc.®

Julie Wijesooriya

Cincinnati Children's Hospital Medical Center

AAHRPP

Association for the Accreditation
of Human Research Protection Programs, Inc.®

Tonya Ferraro

AAHRPP

AAHRPP
Association for the Accreditation of Human Research Protection Programs, Inc.®

2025 AAHRPP Webinar Series

Learning from Improving through Participant Feedback

Adam Gleeson

Director, Global Participant Enrollment Operations

Celerion

Disclosure Statement

I have no relevant personal/professional/financial relationship(s) with respect to this educational activity

Why Participant Feedback Matters

- Participant retention and engagement directly impact overall study health
- A participant's research experience often extends beyond the individual
- Participant responses may reveal gaps in education and understanding

How Electronic Surveys Started

- CARE teams were formed to implement process and program improvements for study participants
- Increasing participant volume and trial complexity created demand for real-time feedback
- Participant complaints and feedback were not being collected in a centralized location

Feedback in Action

- Two types of electronic surveys were created
  - Service requests (extra pillows, new board game, new activity idea, etc.)
  - End of Study Satisfaction
- Both surveys can be completed anonymously
- QR codes were created for each survey and placed in high traffic areas throughout the clinic (participant info boards, cafeteria tables, etc.)

Assessing Quality and Satisfaction

- Feedback that is submitted is sent directly to the CARE team for immediate review and action
- Operational review on a monthly level to assess KPI's and identify potential enhancements
- Monthly summaries are distributed to clinic staff highlighting positive and negative feedback, with special recognition for staff mentioned positively.

Feedback Implementation

- Common complaints and questions help form the creation or revision of existing participant materials to address knowledge gaps.
- Feedback is shared with the clinical operational teams for awareness during study setup and design
- Facility updates that might otherwise be overlooked are identified and addressed

Results

- Increased staff recognition and performance improvement
- Heightened focus on participant satisfaction
- Timely responses to feedback help build trust between staff and participants

How To Get Started

- Review your current process on gathering participant feedback:
  - What are your goals for feedback? What do you want to see?
  - Are the questions clear and concise?
  - Responses answered to in a timely manner?
  - Who is responsible for handling the responses?

Tips To Consider

- Limit the number of questions
- Offer anonymity
- Encourage but not require participation
- Establish KPI's and measurable goals
- Remember: responsiveness goes a long way!

AAHRPP
Association for the Accreditation of Human Research Protection Programs, Inc.®

2025 AAHRPP Webinar Series

Increasing Community Access to Clinical Trials and to Broader Research Participation

Francesca Gany, M.D., M.S.
Chief, Immigrant Health and Cancer Disparities Service
Nicholls-Biondi Chair in Community Health Equity
Memorial Sloan Kettering Cancer Center

Disclosure Statement

I have no relevant personal/professional/financial relationship(s) with respect to this educational activity

AAHRPP Association for the Accreditation of Human Research Protection Programs, Inc.®

MSKCC Immigrant Health and Cancer Disparities (IHCD) Center

Mission

To promote health justice and equity for minoritized, low socioeconomic status, immigrant, and other underserved communities

locally, nationally, globally

Research, Outreach, Patient and Community Engagement, Service Delivery, Training, Program and Policy Development

Interrelated

We use a social determinants lens in all of our work

AAHRPP Association for the Accreditation of Human Research Protection Programs, Inc.®

Addressing Social Drivers of Cancer Disparities Facilitates Research Participation

Language

Literacy+Digital Divide

Culture

Care Affordability and Accessibility

Insurance

Financial Toxicity of Treatment

Income

Employment/Employment Outcomes

Food Security (Risk and Outcomes)

Housing

Transportation

Immigration Status/Fears+Systemic Racism

Trust

Priorities

Neighborhood Deprivation

NYC Demographics

Category	Percent
Race	
White alone	39.8%
Black or African American alone	23.4%
Asian alone	14.2%
American Indian and Alaska Native alone	0.5%
Native Hawaiian and Other Pacific Islander alone	0.1%
Two or More Races	7.1%
Hispanic/Non-Hispanic	
Hispanic or Latino	28.9%
Nativity	
Foreign-born*	37%

Sources: U.S. Census Bureau; https://www.nyc.gov/site/opportunity/reports/immigrant-economic-profile.page

Socioeconomic Indicators

Category	Percent
Poverty/Near Poverty	>50%
Struggling to make ends meet	50%
Rent-burdened	50%
Food insecure	14-20%

Over 50% in many safety net cancer clinics

* Over 150 countries of origin represented in NYC

Limited English Proficiency (LEP)

Communication is the cornerstone of effective cancer education, care, and research participation

9% of US population has LEP

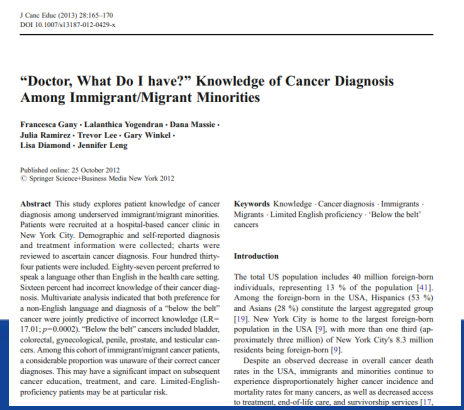
25% of New York City Residents have LEP

Spanish, Chinese languages, Russian, Bengali, Haitian Creole, Korean, French

19% of Californians LEP

17% of patients with LEP in safety net / comprehensive cancer center clinics

did not know their cancer diagnosis



J Canc Educ (2013) 28:165–170
DOI 10.1007/s13187-012-0429-x

"Doctor, What Do I have?" Knowledge of Cancer Diagnosis Among Immigrant/Migrant Minorities

Francesca Gany · Lalanthica Yogendran · Dana Massie · Julia Ramirez · Trevor Lee · Gary Winkel · Lisa Diamond · Jennifer Leng

Published online: 25 October 2012
© Springer Science+Business Media New York 2012

Abstract This study explores patient knowledge of cancer diagnosis among underserved immigrant/migrant minorities. Patients were recruited at a hospital-based cancer clinic in New York City. Demographic and self-reported diagnosis and treatment information were collected; charts were reviewed to ascertain cancer diagnosis. Four hundred thirty-four patients were included. Eighty-seven percent preferred to speak a language other than English in the health care setting. Sixteen percent had incorrect knowledge of their cancer diagnosis. Multivariate analysis indicated that both preference for a non-English language and diagnosis of a "below the belt" cancer were jointly predictive of incorrect knowledge (LR= 17.01; $p=0.0002$). "Below the belt" cancers included bladder, colorectal, gynecological, penile, prostate, and testicular cancers. Among this cohort of immigrant/migrant cancer patients, a considerable proportion was unaware of their correct cancer diagnoses. This may have a significant impact on subsequent cancer education, treatment, and care. Limited-English-proficiency patients may be at particular risk.

Keywords Knowledge · Cancer diagnosis · Immigrants · Migrants · Limited English proficiency · "Below the belt" cancers

Introduction

The total US population includes 40 million foreign-born individuals, representing 13 % of the population [41]. Among the foreign-born in the USA, Hispanics (53 %) and Asians (28 %) constitute the largest aggregated group [19]. New York City is home to the largest foreign-born population in the USA [9], with more than one third (approximately three million) of New York City's 8.3 million residents being foreign-born [9].

Despite an observed decrease in overall cancer death rates in the USA, immigrants and minorities continue to experience disproportionately higher cancer incidence and mortality rates for many cancers, as well as decreased access to treatment, end-of-life care, and survivorship services [17,

AAHRPP
Association for the Accreditation of Human Research Protection Programs, Inc.®

Building Research Participation Infrastructure and Trust

Language Infrastructure

Training
Transcreation
Remote Simultaneous Interpreting (R01)
AI Systems (U54)

Community Partneer Platform + Navigation Infrastructure

Integrated Cancer Care Access Network (ICCAN)

Mobile Health Unit (MHU)

Launched 2021

AAHRPP
Association for the Accreditation of Human Research Protection Programs, Inc.®

Language Access Infrastructure: Linguistic and Cultural Responsiveness Shared Resource Core

Provider non-English Language Competencies

Interpreter Screening and Training

Materials/Instruments Transcreation(includes cultural adaptation)

Conduct/Analyze Qualitative Research

Bilingual Service/Research Navigators → Entry into clinical research, multilingual qual/quant research, CBPR

Remote Simultaneous Medical Interpreting (UN-style)→AI-RSMI

AAHRPP
Association for the Accreditation of Human Research Protection Programs, Inc.®

Interpreter Training: Reducing Errors in Communication Across the Language Barrier

Study: Interpreter Training and Patient Safety

- Scripted Breast Cancer Encounters: Trained and U&C Interpreters
- Analyzed with an Error Analysis Tool
  - 27% of errors made by **untrained** interpreters of moderate or greater clinical significance vs. 8.5% of errors made by **trained** interpreters
  - Vocabulary precision rate .69 for trained vs. 0.34 for the untrained

Dr: The results were positive which means that you carry the gene that puts you at risk for developing breast cancer

Int: The results were correct

Dr: One important thing that you have going for you is the fact that the cancer has probably been caught early

Int: One important thing is the fact that the cancer is working quickly in your body

Dr: The doxorubicin could hurt your heart

Int: The doxorubicin can give you pain

Patient Satisfaction with Different Interpreting Methods: A Randomized Controlled Trial

Francesca Gany, M.D., M.S.[1], Jennifer Leng, M.D., M.P.H.[1], Ephraim Shapiro, M.B.A., M.P.A.[1], David Abramson, Ph.D., M.P.H.[2], Ivette Motola, M.D., M.P.H.[3], David C. Shield[4], and Jyotsna Changrani, M.D., M.P.H.[1]

[1]Center for Immigrant Health, Department of Medicine, New York University School of Medicine, New York, NY, USA; [2]Columbia University Mailman School of Public Health, New York, NY, USA; [3]Jackson Memorial Medical Center, University of Miami, Coral Gables, FL, USA; [4]Yale University School of Medicine, New Haven, CT, USA.

BACKGROUND: Growth of the foreign-born population in the U.S. has led to increasing numbers of limited-English-proficient (LEP) patients. Innovative medical interpreting strategies, including remote simultaneous medical interpreting (RSMI), have arisen to address the language barrier. This study evaluates the impact of interpreting method on patient satisfaction.

BACKGROUND

Growth of the foreign-born population in the United States has led to increasing numbers of limited-English-proficient (LEP) patients. The LEP population (defined as speaking English less than very well) increased from 14 million in 1990 to 21.4 million in 2000.[1] Language discordance between patients and their medical providers is a major factor impeding effective

Engaging Community Through Shared Partnerships

- CCNY in Harlem
- First Gen Students
- Research, Education, Community Outreach

CCNY/MSK U54 Partnership

- Occupation based
- Chinese, Hispanic, West African, Arab, South Asian

Community Partnerships and Consulates

- Jamaica Hospital
- NYC H+H
- FQHCs
- Community MDs

Safety Net Facility Partnerships

Global Partnerships

- FIPOL (Latin America)
- ARGO (West Africa)

MSK Integrated Cancer Care Action Network (ICCAN)

Network of 364 organizations/resources

Community members/CBOs

Providers

Researchers

Facilities and administrators

Program and policymakers

SOCIAL RISK RESOURCES

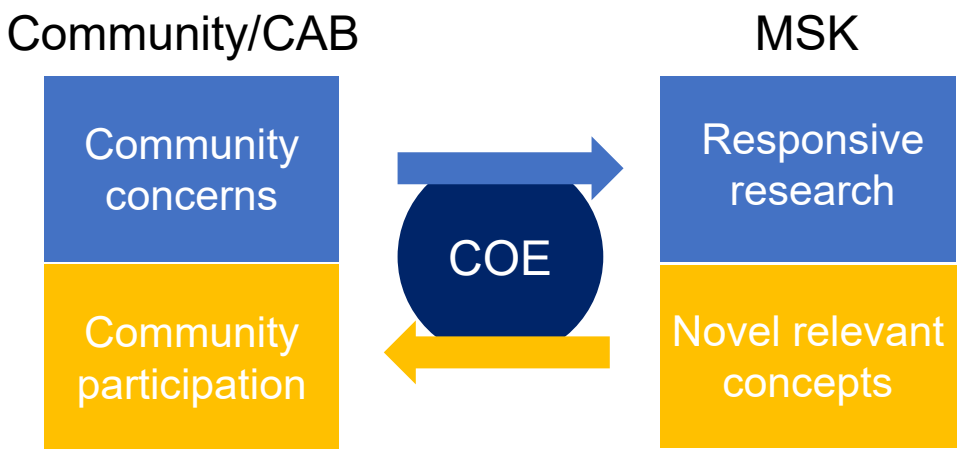
TRUSTED CABS
Research/Clinical Trials Ed
Study Co-Creation-Implementation
CBPR: Taxi Network, SA Health Initiative, SANOS

BILINGUAL NAVIGATORS
Essential Needs (e.g., Food)
Systems Linkages (e.g., Telehealth)
Systemwide SDoH Screening
Navigators Screen All Patients for Clinical Trials Awareness, Interest, Participation Needs

AAHRPP Association for the Accreditation of Human Research Protection Programs, Inc.®

Further Supporting Community Engagement in Research at MSK

Bidirectional germination of new community-based research and projects



COE Facilitation

- Defining areas of alignment
- Establishing project-specific CABs
- Engaging CRTEC for trainee participation
- Communicating implications and future directions

Thank You Community Partners

AAHRPP
Association for the Accreditation of Human Research Protection Programs, Inc.®

Thank You to Our Patients

Thank You to the Immigrant Health and Cancer Disparities Team

Thank You to Our Funders

AAHRPP
Association for the Accreditation of Human Research Protection Programs, Inc.®

2025 AAHRPP Webinar Series

Participant/Community Outreach and Collaboration: Innovative Practices by AAHRPP-Accredited Organizations

The Research Participant Advisory Group (RPAG)

Julie Wijesooriya MPA ~ Research Community Liaison
Cincinnati Children's Hospital Medical Center/University of Cincinnati
Center for Clinical and Translational Science and Training (CCTST)

Disclosure Statement

I have no relevant personal/professional/financial relationship(s) with respect to this educational activity

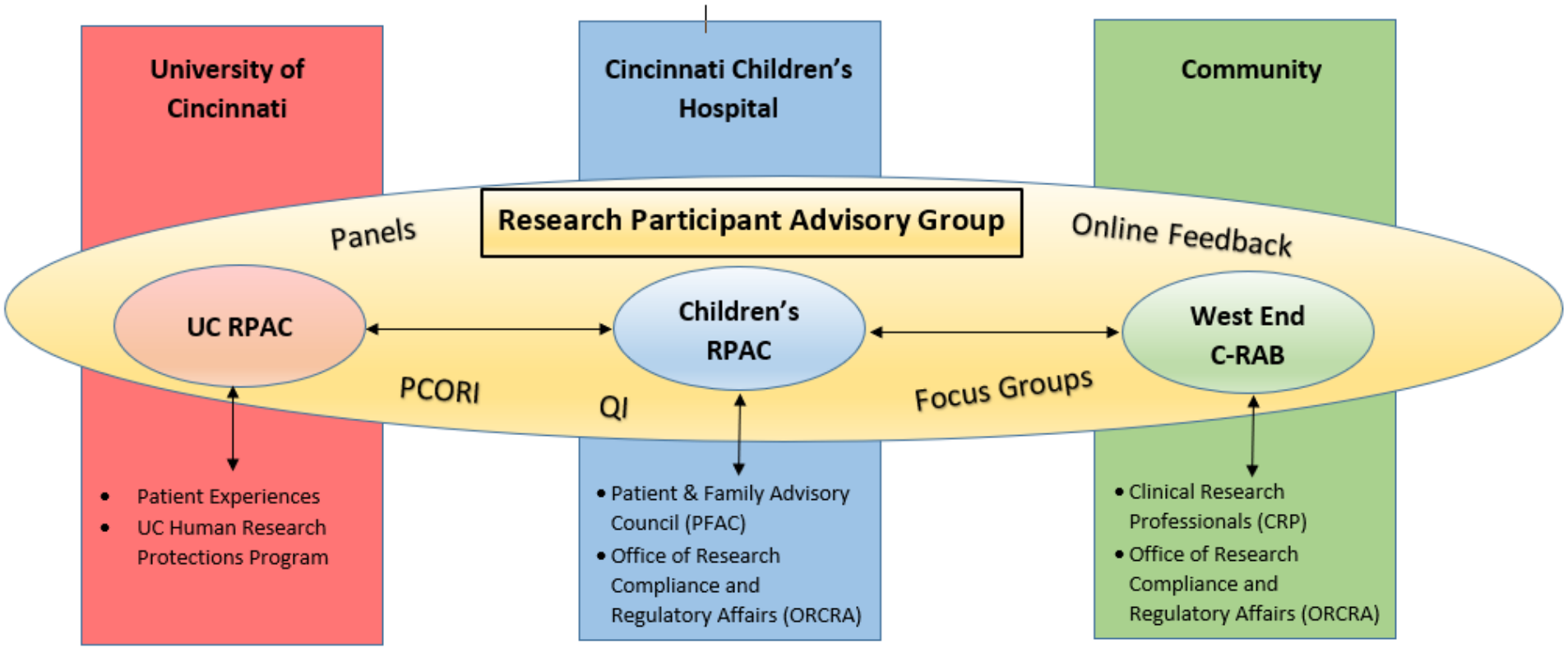
Research Participant Advisory Group (RPAG)

The Research Participant Advisory Group (RPAG) ***provides the structured forum*** *for research participants, family and/or community members…*

… to advise and engage with researchers across the Academic Health Center…

…on research and practices at the medical center and/or out in the Cincinnati community.

RPAG Model


University of Cincinnati
Cincinnati Children's Hospital
Community
Research Participant Advisory Group
Panels
Online Feedback
UC RPAC
Children's RPAC
West End C-RAB
PCORI
QI
Focus Groups
• Patient Experiences
• UC Human Research Protections Program
• Patient & Family Advisory Council (PFAC)
• Office of Research Compliance and Regulatory Affairs (ORCRA)
• Clinical Research Professionals (CRP)
• Office of Research Compliance and Regulatory Affairs (ORCRA)

RPAG: How it Began

- 2015 @ Cincinnati Children's
- Started as **one** advisory council: **Research Participant Advisory Council (RPAC)**
- **Becca Harper, DNP, RN**, Part of Doctoral thesis
- Saw need for input from research participants, just like receive from patients on clinical side
- Modeled after Cincinnati Children's Patient and Family Advisory Council
- I was hired Jan 2016…

Children's Research Participant Advisory Council (CCHMC RPAC)

- Started February 2015
- Modeled after PFAC
- Meet Monthly @ Children's
- Adult/Child Participants & Family Members

- Provide guidance on how to improve research at Cincinnati Children's Hospital, with a focus on the participant experience
- Establish best practices and improvement initiatives
- Humanize the face of research at Cincinnati Children's Hospital

AAHRPP
Association for the Accreditation of Human Research Protection Programs, Inc.®

West End Community Research Advisory Board (WE C-RAB)

- Started June 2016
- Meet Monthly @ Seven Hills Neighborhood Houses
- Focused on community health and research
- West End Community Members

- Humanize research in the West End community and similar communities
- Engage researchers to ensure they support the West End's health goals in addition to collecting study data (CBPR Methods)
- Make research easier and more understandable for West End community members and similar communities
- Guide what research happens in the West End
- Ensure research is mutually beneficial

AAHRPP
Association for the Accreditation of Human Research Protection Programs, Inc.®

University of Cincinnati Research Participant Advisory Council (UC RPAC)

- Started August 2024
- Facilitator: Mo Kelly
- Meet Monthly @ Vernon Manor
- Focused on UC Clinical Research
- UC Research Participants or utilize UC Health

- Providing feedback on specific research requests
- Establishing best practices and improvement initiatives inclusive of community.
- Humanize research at the institution and the surrounding communities.
- Create a space for bi-directional learning.
- Provide a foundation for researchers wishing to include patients and families in their study design.

RPAG Components

How We Began: Start-up Steps

- Steering Committee
- Meet n' Greet presentations
- Flyers, tear pads, targeted potential members
- Potential members interviewed before invitation for demographic representation
- By-laws
- West End C-RAB: election of officers

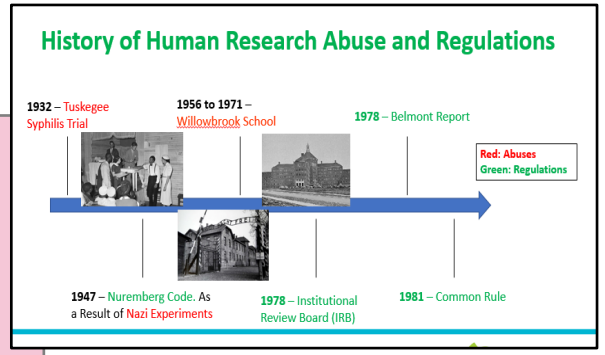
The Ways We Grow: Training/Capacity Building

All members:

- Human Subject Research Ethics Training
- Field trips to research facilities (CCHMC Biobank)
- Guest educational speakers

Also for West End C-RAB members:

- Encourage Community Leaders Institute Training
- Creation of Community Resource Binder
- NIH/NIGMS Science Education Program Award (SEPA) partnership

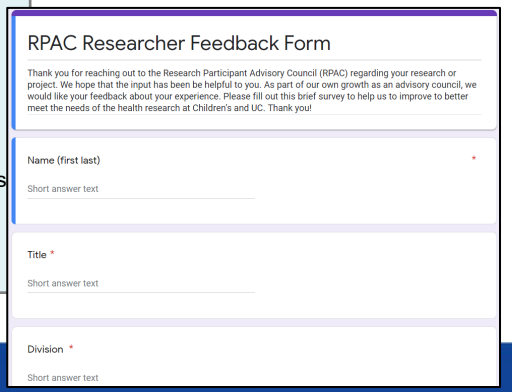


The Ways We Provide Input: Advisory Group Feedback Methods to Researchers

- Whole- and small-group discussions
- Individual interviews/written evaluations
- Focus groups (with non-member participants)
- Formal feedback to IRB protocols
- Individual advisors on projects/study teams
- Remote/electronic review forms and surveys
- Role-playing scenarios

The Ways We Improve: Evaluation Methods

- Annual assessment surveys or interviews
- Post-meeting assessment member surveys
- Pre-application and post-meeting researcher assessments



The Relationships: Research Studies/Projects

REDCap

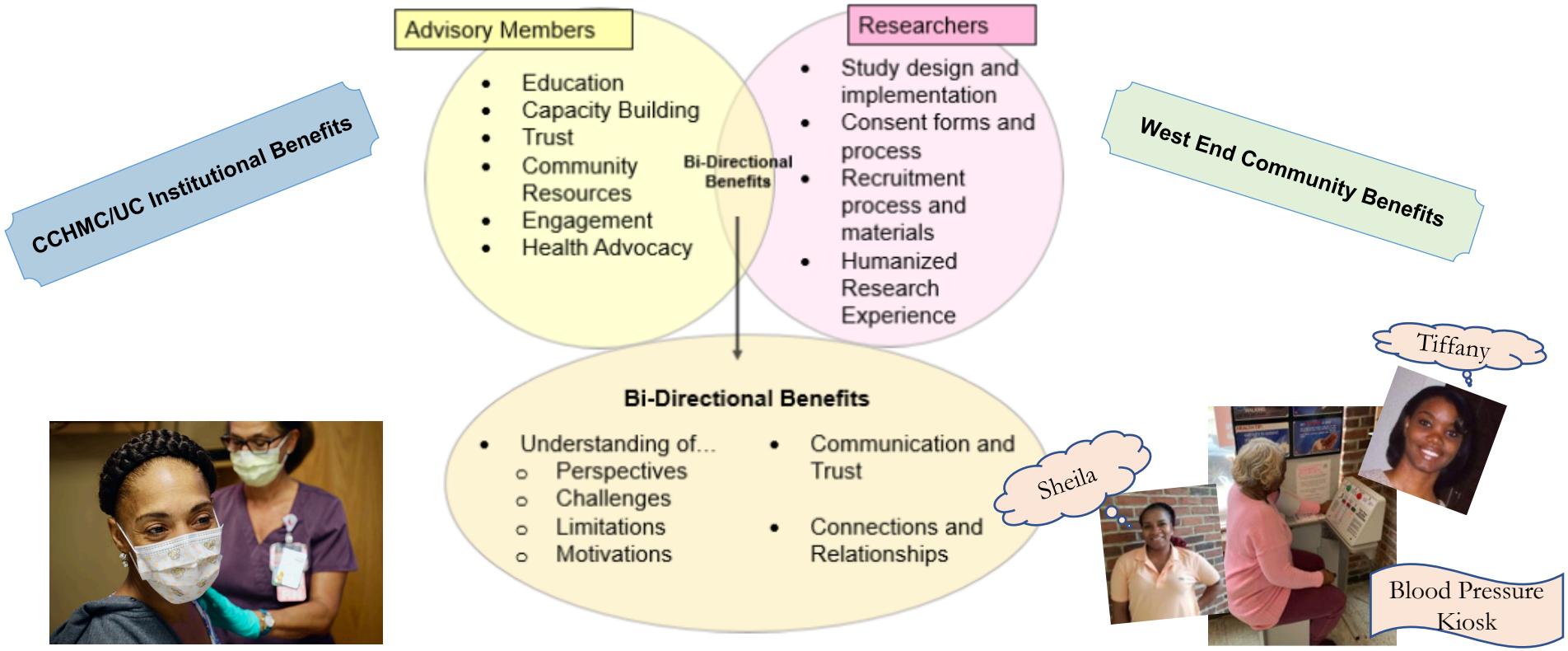
Electronic participant Screener in REDCap for research studies: pilot project

Holly Jones, PhD, RN, CNPUC,
UC College of Nursing (K01 – B-SWELL)

Informed Consent Template Focus Groups:
Common Rule Key Information Section

Melinda Butsch Kovacic, MPH, PhD,
College of Allied Health Sciences, UC (SEPA – WE4H)

Bi-Directional Benefits



Camilla Keesee, RPAC Member,
Participant in Phase I Pfizer COVID-19 Vaccine Trial

Tiffany Grant, PhD, UC Health Sciences Library
(NNLM – Narrowing the Health Gap in Cincinnati)

AAHRPP Association for the Accreditation of Human Research Protection Programs, Inc.®

AAHRP Standard I.4.C

The organization promotes the involvement of community members, when appropriate, in the design and implementation of research and the dissemination of results.

- Revamping the hospital-wide ICF, adding the Key Information section
- Role-playing: mock consent process to obtain feedback or study visit experience
- On-going relationships: with IRB, institutional-wide biobank
- Vaccine research: Education and messaging out in the community
- Community members as study staff: conducting intervention, authors on manuscripts

- Flexibility and versatility to ensure the engagement of community in research
  - From design to dissemination
  - One-off feedback tool for any research aspect to long-term partnership with possible co-creation and mutual benefit
  - Ability to customize to the specific research projects

Questions?