# **COMMUNITY** DIALOGUE GUIDE

A Resource For Researchers To Collaborate with Communities and Improve Their Science

Issued by the Cancer Health Equity Center of Excellence (CHECoE) at the Rutgers Cancer Institute of New Jersey

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For questions and additional information, please contact the Community Outreach and Engagement team at **<u>outreach@cinj.rutgers.edu</u>** 

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A special thank you to the following individuals at the Cancer Health Equity Center of Excellence who contributed to this document:

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### **Guide Overview**

Dear Researcher,

This guide was prepared as a resource to help you engage in bi-directional conversations with community members to improve your research in our Catchment Area (CA), the entire state of New Jersey. NCI defines community outreach and engagement (COE) as an official responsibility of all Cancer Center researchers, regardless of where your work falls in the cancer research continuum.

The guide has been divided into three sections to help you through this process:

- Section 1 Researcher Responsibilities and Community Outreach and Engagement Opportunities
- Section 2 Science Communication Best Practices
- Section 3 Tools, Templates, and Resources

We hope this is a valuable resource and we look forward to helping you collaborate with community members to improve your research.

Thank you!

Cancer Health Equity Center of Excellence (CHECoE) Team

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Researcher Responsibilities and Community Outreach and Engagement Opportunities

RUTGERS Cancer Institute of New Jersey RUTGERS HEALTH

> Community Outreach and Engagement

**NCI** Designated Comprehensive Cancer Center

### NCI Community Outreach and Engagement Requirements

Per the National Cancer Institute (NCI), Cancer Centers occupy a unique and important role in their communities. They are expected to perform research of relevance and engage the populations within their catchment area (CA) in the research they conduct. To accomplish this, Centers thoroughly analyze the demographics and cancer burden of their CA. In addition, Centers are expected to engage communities within their catchment area to decrease their cancer burden, particularly among minority and underrepresented populations.

To facilitate these community outreach and engagement (COE) activities, Centers establish community advisory board(s) and partnerships with other healthcare delivery systems, state and community agencies, and coalitions for dissemination of evidence-based findings.

COE plays a vital role in reducing the cancer burden through continuous engagement and partnerships with community members, healthcare agencies, and community organizations. COE increases awareness of cancer and expands access to cancer prevention, screenings, treatment, research, and survivorship services to improve cancer outcomes. With the goal of advancing and increasing cancer health equity, Cancer Centers are encouraged to coordinate community outreach events, host professional and educational workshops, and share resources in the communities they serve.



### **NCI Requirements for Cancer Center Researchers**

#### What do you need to do?

- When working with community stakeholders, you should identify community needs, align your research program with those needs, and conduct research that is especially relevant to our catchment area population (New Jersey).
- Your research program is required to conduct and report on research projects where outreach and engagement informs communities and results in high-impact science.
- You're also required to work with communities to disseminate and implement evidencebased interventions (EBIs) and guidelines, public education, and public health policy recommendations related to your research.

#### What's in it for you?

Engaging communities is beneficial to your work when identifying research questions, designing and implementing a study or intervention, recruiting study participants, and interpreting findings.

This engagement results in better science and the following likely outcomes:

- More relevant research questions
- Greater recruitment success
- Increased external validity
- Greater retention of participants
- Enhanced understanding of findings

### How The Rutgers Cancer Institute's CHECoE Team Can Help You



The CHECoE team is here to help you engage with communities in New Jersey as required by NCI.

The Cancer Health Equity Center of Excellence (CHECoE) team is dedicated to improving the lives of the diverse populations that reside in our catchment area (NJ) and advancing cancer health equity across the state by collaborating with community partners, a Community Cancer Action Board (CCAB), and Community Scientists.

The CHECoE team helps researchers like you effectively

communicate with lay audiences and facilitate community discussions on how your research can address community needs or concerns while also enhancing the science behind your research. Along with this Community Researcher Guide, our team can facilitate community-researcher engagement with individuals and groups who are able to share feedback and insights relevant to your research.

Additionally, NCI asks you to report on the impact your COE activities have on your research. You can receive confidential and personalized feedback from our team, Community Scientists, and community partners to help you develop comfort and confidence while engaging in community-researcher dialogue.

If you're interested in any of these services, would like to discuss other approaches and options, or wish to collaborate with the CHECoE team, complete our interest form <u>here</u> or contact us at <u>outreach@cinj.rutgers.edu</u> to start a conversation!

#### CHECoE Community-Informed Opportunities and Services

The CHECoE team offers several recurring bi-directional community engagement opportunities to help you participate in dialogue with community members. When participating in any of these opportunities, we strongly recommend the following steps to produce the most benefit to you and your research:



### **Process for Engaging Community Members with Support from COE:**

The CHECoE team offers several recurring bi-directional community engagement opportunities to help you participate in dialogue with community members. When participating in any of these opportunities, we strongly recommend the following steps to produce the most benefit to you and your research:

- **1.** Review Section Two of this Guide.
- **2.** Consult with our team to determine what approach will work best with your research.
- **3.** Use the template COE PowerPoint (in Section Three) to develop and focus your community discussion questions.
- **4.** Preview your COE approach and discussion questions with our team for confidential and supportive pre-review and presentation suggestions.
- **5.** Conduct your community-engaged discussion session with an audience that will provide relevant input and support.
- 6. Document how your COE session went for NCI reporting. Was there impact for your research? What worked well? What other resources or support do you need?

The next few pages of this guide summarize the different formats of COE discussion venue that the CHECoE team routinely coordinate – we are also happy to facilitate other COE approaches as your specific research questions and studies require.

#### Acronyms

CINJ	Rutgers Cancer Institute of New Jersey
CHECoE	Cancer Health Equity Center of Excellence
CCSG	Cancer Center Support Grants
COE	Community Outreach and Engagement
CCAB	Community Cancer Action Board
CA	Catchment Area

The next few pages of this Guide summarize the different formats of COE discussion venues that the CHECoE team routinely coordinate - we are also happy to facilitate other COE approaches as your specific research questions and studies require.

Virtual Chat on Tap

#### Community Scientist Highlights:

- Trains community members on the research process and how to provide impactful review and feedback on research projects
- Generates graduates who provide advice to improve studies in all Rutgers Cancer Institute research programs
- Ensures research plans are reviewed by community members for gaps, problems, and opportunities before, during, and after study implementation

#### Community Scientist Training Program

Our Community Scientist Training Program connects scientists, researchers, and community members with diverse backgrounds and levels of expertise in science and research. In this 9-week training program, participants learn the essentials of the cancer research process including topics such as: Research Ethics, Basics of Research and the Research Process, Clinical Trials, Cancer 101, Cultural Competency, Informed Consent, and Social Determinants of Health. The material is tailored to give community members a strong foundation in the cancer research process so they are equipped to communicate and collaborate with researchers and disseminate information back to their respective communities.

#### How can Community Scientists help your research?

Community Scientists can engage and collaborate with researchers by:

- Advising researchers on different aspects of their research, such as grant proposal input, grant application review, and evaluating outcomes measures,
- Providing feedback on research questions to ensure they align with community needs,
- Reviewing research protocols and giving feedback on protocol language to ensure the research approach and purpose makes sense and is clearly communicated,
- Assisting researchers with recruitment efforts, providing feedback on recruitment plans, and advising on dissemination plans,
- Serving on Rutgers Cancer Institute's Scientific Review Board (SRB), and
- Providing feedback for researchers during Community Science Cafés and other facilitated meetings.



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### **2** Community Science Cafés

Community Science Cafés allow researchers to engage in bidirectional conversations with community members to review specific aspects of research projects (e.g., a recruitment plan, an evaluation plan, a tool to be disseminated, a form to be used, a research question to be investigated, etc.) and get suggestions on how to improve or adjust those materials and approaches for the study's priority populations. The goal is to facilitate opportunities for tangible, impactful feedback for you, the researcher, to take back and implement in your work.

Our Science Cafés typically have upwards of 40 participants including Community Scientists, CCAB members, community partners, and internal staff. They are held via Zoom, and Community Scientists document their feedback and suggestions, which are then shared with you, the researcher.

#### Science Café Highlights:

- Allows you to present an overview of your work and get feedback on specific components of your research plans and approaches
- Ensures insights from community members with a variety of experiences are available to help you improve your science
- Use templates and assistance from CHECoE staff to prepare your research overview and the questions you're seeking guidance on

### COMMUNITY CANCER ACTION BOARD

### CCAB Highlights:

- Opportunity to provide an overview of your work and to engage in conversations with the community members
- You provide a short overview of your work (5-10 minutes) and pose specific questions to CCAB members
- Meetings occur every other month

### **3** Community Cancer Action Board

The Community Cancer Action Board (CCAB) builds and fosters partnerships between cancer researchers and community outreach staff and New Jersey communities. The CCAB provides input from community thought leaders and patient advocates to ensure community outreach and engagement; research activities promote health equity, strengthen local capacity, and are responsive to community needs. All members work together to support the advancement of cancer health equity and reduction of cancer health disparities and cancer burden.

The CCAB helps to build trust and mutual understanding between researchers and the communities we serve, ensuring that values, customs, and cultural differences among persons and communities are respected. Members of our CCAB include educators, non-profit founders, healthcare professionals, community and patient advocates, and cancer survivors.

CCAB Impact Councils serve as internal CCAB committees that focus on specific cancer health equity topics. Impact councils meet regularly and are tasked with sharing their ideas regarding outreach, education, and program implementation related to their focus topics. Each impact council is co-led by internal staff and CCAB members.

#### **4** Catchment Area and COE Research Program Integration Meetings

The CHECoE holds quarterly Catchment Area and COE Research Program Integration meetings where CCSG Program Leaders describe how research in their respective program is addressing CA priorities and bi-directionally engaging relevant communities. These meetings focus on current research efforts and possible future directions, followed by open discussion. Meetings include COE Program Liaisons from the five CCSG research programs and are open to the community (CCAB members and Community Scientist graduates) as well as all faculty and staff.





### **5** Works in Progress Meetings

The CHECoE team helps researchers connect with other researchers in the Rutgers community on topics relevant to cancer health disparities through Works in Progress (WIP) meetings. WIP meetings allow faculty to talk with other scientists about their research ideas, designs, and how to engage the community for input as well as to get peer feedback in an informal setting.

Research can be presented at all stages: starting a project, planning the design, analyzing the data, or preparing for a grant submission. The objective is to set a reasonable agenda with plenty of time to ask focused questions to elicit feedback and discussion. Researchers typically use this opportunity to obtain feedback from their fellow researchers at the following stages:

#### **Research Proposal Planning**

- Identify the gap(s) in the literature
- Focus on 1-2 issues / dilemmas, for example:
  - Present/refine your conceptual framework
  - Identify possible research questions/hypotheses
  - Discuss pros/cons of research methodologies
  - Identify potential data sets
  - Solicit ideas on mentors, collaborators, funding sources, and ideas on when and how to engage with community members.

#### **Study Design and Data Analysis Planning**

- · Briefly present what's been done as it affects your design
- · Identify your specific aim(s) and hypotheses
- Present your research design
- Focus on 1-2 issues / dilemmas for example:
  - Research design:
  - Are these appropriate inclusion / exclusion criteria?
  - How can I improve recruitment?
  - Request feedback on questionnaires.
  - How can I get my protocol through the IRB?
  - How can I collect data on other variables in my conceptual framework?

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#### Data analysis:

- Do the variables in my model make sense?
- Here's an interesting finding what do you think of my conclusions?
- Are there other confounders to consider?

### **Section 1 Summary**

Remember to think about how your work has been impacted by COE discussions, as the CHECoE team will be following up to track this information with you. CCSG program members are expected to take advantage of these opportunities and provide specific examples of how your research benefited from community outreach through CCAB, Science Cafés, Impact Councils, focus groups with community members, and other approaches to engage with community members in the Catchment Area.

### Questions to consider when thinking about the impact of community engagement:

- Did the feedback take your research in a different direction?
- Did you gain insight into strategies to help promote your research (enrollment, dissemination, etc.)?
- Did engagement expand your reach to other communities and other populations?
- Did you improve study materials?
- Can you describe specific examples of how community members benefited from learning about your research?
- · Were you invited to community meetings as a result of your engagement?
- Were you invited to share materials with other populations as a result of your engagement?

To learn more or consult with our team, complete our interest form or contact us at <u>outreach@cinj.rutgers.edu</u> to start a conversation!

# SECTION

# Techniques, Suggestions, & Strategies



### Section Highlights:

- You can effectively present research to community members to obtain useful feedback
- Be clear on the reasons why you're engaging community members
- Stay away from simply summarizing the research being done and asking what the audience thinks of it

### Effectively Communicating Your Science

New Jerseyans deserve clear communications from researchers and medical professionals. We hope you find this section useful and that it helps you improve your communication strategies.

The tips in this guide are effective for any form of communication, but they are most relevant to presentations and written information regarding research. The following recommendations are adapted from Federal Plain Language guidelines as well as resources from NCI and other national organizations focused on improving the usefulness and effectiveness of communications by scientists, researchers, and technical experts when working with the public. See the references page <u>here</u> to learn more and explore these resources.

Our goal is to provide you with the tools and strategies necessary to communicate effectively with your audience by sharing actionable, understandable information and receiving actionable, relevant information that improves your research.

This section covers effectively communicating your science by:

- Setting your goals and knowing your purpose,
- Defining your audience and which communities to engage,
- Organizing your information,
- Choosing words and phrases so you're understood,
- Using plain language,
- · Effectively using visuals, diagrams, and graphics, and
- Asking questions to get useful answers.



### **Setting Your Goals and Knowing Your Purpose**

COE is not a check-the-box activity meant to stress you out, take time away from your research, or make your work more complicated. Engaging communities in your research, when done thoughtfully, can dramatically improve your science from start to finish! Feedback from relevant community members can help you more effectively identify research questions, design and implement the study or intervention, recruit and retain study participants, and interpret findings. But how?

Present more than a summary of your work. If you go in with a goal of "tell the audience what you're working on and ask them if they understand," then that is all you will accomplish. Instead, define two or three specific things you would like to get out of your community engagement experience. Examples include:

- How can I improve or adjust my recruitment strategy to better connect with Black breast cancer survivors?
- If my study focuses on management of pain during cancer treatment, how should I assess pain levels in older men of different backgrounds and ethnicities?
- Are there any terms in my study protocol that community members or lay individuals may not understand?

By defining what you want to achieve or learn from your community reviewers, you can customize your presentation to provide your reviewers with the information they need to best help you. If your audience doesn't know what you want from them, they'll have a hard time providing relevant feedback. Community outreach and engagement are tools that, when used effectively, lead to more relevant research questions, greater recruitment success, increased external validity, greater retention of participants, and enhanced understanding of findings.

#### Key Points:

- Focusing on your audience while preparing your presentation will ensure the feedback received is relevant to your needs and benefits you
- Stay away from simply summarizing the research being done. Have goals established for aspects of your research you'd like to improve
- Come prepared. Know the reasons why you're engaging community members



### Key Points:

- Use the list of questions on this page to tailor your approach
- Take your audience's current level of knowledge into account when developing your presentation and approach
- Align your communications with your audience's needs so they can effectively engage in dialogue regarding your research

### Define Your Audience and Which Community To Engage

Now that you know why you're engaging with the community about your research, it's time to determine which community you should engage with. What group of people are going to have the best insights and expertise on the questions you're trying to answer?

The best way to grab and hold someone's attention is to figure out who they are and what they want to know. Tell your audience why the material is important to them.

Identifying your audience will ensure that you communicate clearly and help you focus on the audience's needs. Start out by thinking about what your audience knows about the situation now. Then, think about how to guide them from their current knowledge to what you need them to know. To help you do this, try answering the following questions:

- Who is my audience?
- What does my audience already know about the subject?
- What does my audience need to know?
- What questions will my audience have?
- What's the best outcome for my research? What do I need to say to get this outcome?
- What's the best outcome for my audience? What do I need to say to get this outcome?

One of the most problematic communication myths is that you have to "dumb down" your content so that everyone everywhere can understand it. That's not true. What you should do is communicate clearly with your specific audience.

Take your audience's current level of knowledge into account when developing your presentation and approach. When you make sure you know who your audience is and clearly communicate with them, you're more likely to get useful feedback and create a productive dialogue that accomplishes your goals.

One of the most effective ways of getting an audience to engage with your work is to make sure they understand how it's relevant to them (WIFM – "What's in it for me?"). Have you explained:

- Why is your research important? Why would someone spend time and money studying this?
- How can your research benefit people including people in your audience?
- What do you want the audience to help you with?
- What could the positive impacts of their involvement be for people like them?



### Organizing Your Information

Organization is key. Start by stating your purpose and exactly what you want help with. Put the most important information at the beginning and include background information (when necessary) toward the end. If you tell your audience what they are going to hear about, they are more likely to be able to follow along.

Establish a context for your audience before you provide them with the details. If you flood your audience with details first, they may struggle to understand what you're talking about. Don't make readers hold a lot of information in their heads before you get to your point. You may need to be especially inventive to translate complicated research approaches into more manageable language.

**Organize to meet your audience's needs:** Think through the questions your audience is likely to ask and then organize your material in the order they would ask them. Another useful organizing principle is the "inverted pyramid style" where you put general information first, with specialized information or exceptions to the general information later. You begin with the shortest and clearest statement you can make about your topic, putting the most important information at the start and the background at the end.

**"Chunk"** your content: Don't try to pack everything into long paragraphs or dense slides. Split topics up into smaller, logical sections defined by informative headings or titles.

**Be brief:** Long, dense talks and presentations are difficult to understand. Short sections and low-density slides are easier to comprehend, and help you organize your information more effectively. Use only the information your audience needs to achieve their tops tasks. Omit unnecessary information.

**Use direct address:** Remember that even though your information may affect thousands or millions of people, you're speaking to specific individuals. You can avoid awkwardness by using "you" to address your audience directly, rather than using "one might ask", "reviewers", "he or she", or other vague or impersonal phrases.

**Choose your words and organization carefully:** Start with your main idea – Don't start with an exception. Word order does matter, so place your words carefully. Complexity is the greatest enemy of clear communication.



#### Key Points:

- Prepare your presentation in an organized fashion so your audience can follow along and absorb the information
- Eliminate filler words and information **be brief!**
- Stay away from complex words
   that require explanations

#### The Inverted Information Pyramid

### General Information

Specialized Information



### Key Points:

- Use words like "we" and "you" to sound more approachable and make your document or presentation is easier to read
- Remove unnecessary words and information - don't waste your audience's time
- Be mindful of vocabulary choice
- Use active voice to make it clear
   who is doing what
- Stick to present tense for clarity

### Choose Words and Phrases So You're Understood

Words are the most basic building blocks of written and spoken communication, and the words you choose can determine whether your audience will have a strong, concrete understanding of the research you present or will have no idea what you're trying to say and ask.

Choose your words carefully – be precise and concise. Here are a few tips to help you communicate clearly:

- Speak directly to your audience: Audience members are more likely to understand what their roles are when you directly address them.
- Omit unnecessary words: Be concise. This can be difficult for a subject matter expert, so it's important to have someone look at the information from the audience's perspective.
- Use short, simple words: Research, clinical, and scientific writing is often stodgy, full of long, dry technical jargon. Use familiar and community-friendly terms.
- Use active voice and present tense: It eliminates ambiguity about responsibilities. Not, "It must be done," but, "You must do it." Passive voice obscures who is responsible for what. In an active sentence, the person or organization that's acting is the subject of the sentence. In a passive sentence, the person or item that is acted upon is the subject of the sentence. Likewise, frequently using conditional or future tense makes it harder for your audience to understand your meaning, so use present tense.



### **Use Plain Language**

#### **Avoid Jargon**

Research jargon are special words that are used by researchers and are often difficult for others to understand; specialists often fail to realize that the terms they use regularly are unfamiliar to all but others in their specialty.

Jargon is unnecessarily complicated, technical language used to impress, rather than to inform, your audience. We're not advocating leaving out necessary technical terms; we are saying to make sure your language is as clear as possible.

Special terms can be useful shorthand within a group and may be the clearest way to communicate inside the group. However, going beyond necessary technical terms to write in jargon can cause misunderstanding or alienation, even if your only audience is other specialists.

#### **Avoid Acronyms and Abbreviations**

Acronyms and abbreviations are intended to help the audience by shortening long phrases. However, they have proliferated so much in current scientific communications that they constantly require the audience to look back to earlier pages or to consult an appendix to puzzle out what's being said.

The best solution is to find a simplified name for the entity or concept you want to abbreviate – for example, "the Cancer Center" instead of "Rutgers Cancer Institute" or "drugs that can stop growth of certain cancer cells" instead of "histone deacetylase (HDAC) inhibitors". This gives readers meaningful content that helps them remember what you're talking about.



**Example:** You're studying prevalence of BRCA1 and BRCA2 in a specific patient population and are seeking feedback on how to handle patient consents and specimen collection. Instead of calling these BRCA1 and BRCA2 throughout your discussion, define them at the start of your talk and then, for the remainder of your talk, simply call them "the breast cancer genes we're studying" – there's no need to keep using the acronym when a plain language phrase is available.

### Key Points:

- Refer to the NCI's Cancer Dictionary if you're unsure of whether a term is jargon; if it's in the list, strongly consider using the plain language from NCI's definition of the term instead
- Define any technical words that are necessary to describe your research
- Terms that are familiar to you
  may not be familiar to others
- Limit the use of acronyms and abbreviations; only use if they make it easier, not harder, for your audience to understand

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### **Communicate** Information Visually

When visually presenting text and when including visuals, diagrams, and graphics in your communications, you should:

#### 1. Use examples

Examples can help you communicate complicated concepts and can help your audience understand in real terms why your research is useful. Use examples in lieu of long, abstract explanations - be specific, concrete, and brief!

#### 2. Use lists

Bulleted lists in documents and presentations are an ideal way to present items, conditions and exceptions. Lists can:

- · Highlight levels of importance,
- · Help the user understand the order in which things happen,
- Make it easy for the user to identify all necessary steps in a process, and
- Add visual space for easier reading.

Tips for effective lists include:

- Using solid round, square, or arrow-shaped bullets,
- Using an introductory phrase to explain the contents of the list,
- Aligning text to the left of the page (never center or right-align a list),
- Using the same grammatical structure for each bullet, and
- Making sure that each bullet is a complete sentence when combined with the introductory phrase.

#### 3. Use emphasis to highlight important concepts

Use **bold** and *italics* to make important concepts stand out. Limit emphasis to only the most important information.

PUTTING EVERYTHING IN CAPITAL LETTERS IS NOT A GOOD EMPHASIS TECHNIQUE. Although it may draw attention to the section, it makes it harder to read and can be viewed as a yelling or shouting.

Similarly, underlining will draw the user's attention to the section, but it makes it hard to read. It's better to use limited bolding and italicizing to highlight the most important content.

### Key Points:

- Use examples to help clarify complicated concepts
- Use lists to highlight important information
- Use bold and italics to emphasize
   the most important points
- Use visuals, diagrams, and graphics only where they quickly and clearly explain a critical concept or data point



Visuals and graphics can help to quickly and effectively communicate healthcare and scientific information to both community members and your medical and scientific peers. However, when used without care, visuals can harm rather than help your effort to communicate.

#### Use the following five tips to effectively visualize your science:

- **1. Tell a story –** Determine exactly what message you want your visual to communicate. What is the narrative purpose of the visual? If you can't figure this out, neither will your audience.
- 2. Tailor your message for your audience Are they familiar with the topic at all? How quickly will they be able to decipher your visual? What necessary information will your visual provide to help your audience give you effective feedback?
- 3. Communicate accurate information Is your visual scientifically and medically accurate? Sometimes, to maintain accuracy, you need to include less rather than more in a visual – you don't need to teach the audience everything about a topic in a visual they will see for only a few minutes.
- 4. Choose the right visual Pick graphics that communicate your intended information better than words – if a viewer can't quickly understand the core information or if the graphic isn't making the information substantially clearer, just skip it!
- Less is more; simplify! Your visual should be so clear that it immediately communicates the intended message. Each visual should have a single message it is trying to communicate; don't mix messages.

This graphic from the NCI is a great example of an effective single message but could be improved by removing the pop out box. That box adds a second, different message that adds complexity.



Source: https://www.nih.gov/research-training/advances-colorectal-cancer-research

The information on this page is adapted from the European Medical Writers Association journal article "Visualisations in science communication: Friend or foe?" by Mariella A.M. Franker. For the full article, visit https://journal.emwa.org/visual-communications/visualisations-in-science-communication-friend-or-foe/

### **Ask Questions** to Get Useful Answers

When thinking about what questions to ask your audience, consider using the PICO Model. This model is a useful tool for generating questions that can be used to engage community members.

PICO stands for patient/population, intervention, comparison, and outcomes. The following chart provides examples of questions that can be generated to address different aspects of your research:

Patient / Population	Intervention	C Comparison	Outcomes
Who is your patient?	What do you plan on doing for the patient?	What alternatives are you considering?	What do you wish to accomplish?
Age, sex, race	Diagnostic test	Another test, medication, or procedure	Accurate diagnosis
Primary problem	Medication	Watchful waiting	Relieve or improve symptoms
Health status	Procedure		Maintain function

When seeking feedback and input from your audience, ask open-ended questions and save "yes/no" questions for polls. Yes/No responses don't provide specific information.

Avoid questions that can be interpreted as patronizing or antagonistic by the listener, such as, "What don't you understand about this?" Instead, focus on how you can improve with questions such as "How can I adjust my approach to make this clearer?"

#### Key **Points:**

- Use the PICO model to develop questions about your research
- Minimize the use of Yes/No questions when seeking feedback and guidance
- Focus questions on how you can adjust or improve
- Visi<u>t https://mcw.libguides.com/</u> EBM/PICO and https://libguides. mssm.edu/ebm/ebp\_pico\_to learn more about the PICO Model and how to use it effectively



## Tools, Templates, and Resources

#### Headline PRESENTATION



Headline profile





Headline profile

This section provides a PowerPoint presentation template, word choice suggestions, and other resources to help you prepare for and get the most out of your engagement efforts. The CHECoE team is here to support you throughout this process, so review these resources and confer with our team to coordinate your outreach approaches.

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### **Community Researcher Presentation Template**

When preparing for community outreach and engagement around your research, use the <u>Community Researcher PowerPoint template</u> to create presentations that are aligned with your goals and that focus on effective dialogue with your audience.

The template is structured around the following questions to guide your presentation and support discussion:

- What are you looking for help on today?
- How can talking to this group of people be mutually beneficial?
- What does the group need to know?

Remember to highlight the most important aspects of your research and focus your presentation on the key information needed by your audience. Your presentation should be concise – use only five content slides that present the following information:

- 1. What you're studying what research question you're asking
- 2. Why you're studying that why it's important to answer that question
- 3. How you're approaching or planning to approach the question
- 4. What's special or new about your approach
- 5. Where you are in this process

After presenting your five context-setting slides, shift to a discussion format focusing on your question(s) for the audience.



### Key Point:

The more time spent on background content, the less useful your discussion feedback will be. Don't waste time!







### Sample Questions to Elicit Feedback

Choose discussion questions from this list or create your own questions to effectively catalyze a group discussion regarding your research and to maximize the feedback you receive:

- What does this research mean to your community?
- Which communities may be helped or harmed by this research?
- How can this be communicated to help the intended audience?
- What are some opportunities for improvement with this approach?
- Which communities/groups could we be missing or not effectively reaching with this approach?
- What challenges might the community face when trying to access or benefit from this research?
- How and why does the intended population engage with [topic] on [location/format]?
- How does the intended population assess credibility of [topic/ information source]?
- In what ways does [information source] lead to action in the intended population?
- How can my recruitment materials be improved to work better for the intended population?
- What terminology used in this study or presentation are not appropriate for the intended population?
- What considerations (e.g., cultural, language, tone, approach, timing, etc.) should be considered to improve this approach?





### Vocabulary List: Cancer and Health Equity Terms

Here are a few words and phrases that should be avoided and recommended explanations to use instead when communicating with audiences that don't have a background in cancer research and cancer care.

Term to avoid	Suggested alternative	Comment
the poor low-class people poor people	people whose incomes are below the federal poverty threshold people whose self-reported incomes were in the lowest income bracket	Many people find the terms "low class" and "poor" pejorative. Use person- first language instead. Define income brackets and levels if possible.
special needs physically challenged mentally challenged mentally retarded handi-capable	person with a disability person who has a disability disabled person people with intellectual disabilities child with a congenital disability child with a birth impairment physically disabled person person with a physical disability	Use person-first or identity-first language as is appropriate for the community or person being discussed. The language used should be selected with the understanding that disabled people's expressed preferences regarding identification supersede matters of style. Avoid terms that are condescending or patronizing.
Referring to people as their race/ethnicity (for example, Blacks, Hispanics, Latinos, Whites, American Indians, etc.) Referring to people as colored people, colored Indian (to refer to American Indian) Non-White (used with or without specifying non- Hispanic or Latino)	American Indian or Alaska Native persons/communities/ populations Asian persons Black or African American persons; Black persons Native Hawaiian persons Hispanic or Latino persons People who identify with more than one race; people of more than one race; persons of multiple races	Consider racial/ethnic groups as proper nouns and capitalize (for example, Black, White). When describing a combination of racial/ethnic groups (for example, 3 or more sub-groups) use "people from some racial and ethnic groups" or "people from racial and ethnic minority groups".

For glossaries of terms and phrases relating to equity and inclusion, visit JAMA <u>https://jamanetwork.com/pages/inclusive-language</u> and CDC <u>https://www.cdc.gov/healthcommunication/Preferred\_Terms.html</u> and APA <u>https://www.apa.org/about/apa/equity-diversity-inclusion/language-guidelines</u>



### Vocabulary List: LGBTQ+ Terms

Here are a few words and phrases that should be avoided and recommended terms to use instead when communicating with and about community members from the LGBTQ+ population.

Term to avoid	Suggested alternative
Sexual preference	Sexual orientation or orientation
Gay rights, special rights	Equality for LGBTQ+ people
Preferred pronouns	Pronouns
Sex change	Transition

	Key Terms and Definitions
Sexual orientation	Includes straight (heterosexual), lesbian, gay, bisexual, queer, asexual, or other orientations that describe sexual preference
Transgender	People whose gender identity differs from the sex they were assigned at birth
Nonbinary	People who experience their gender identity and/or gender expression as falling outside the binary gender categories of man and woman
Pansexual	A person who has the capacity to form enduring physical, romantic, and/or emotional attractions to any person, regardless of gender identity
Gender identity	A person's internal, deeply held knowledge of their own gender
Sex assigned at birth	The sex that is visually expressed and defined by healthcare providers at birth; this is almost exclusively defined as male or female regardless of the person's chromosomes or gender identity

For a comprehensive glossary of terms relating to LGBTQ+ identities, visit **PFLAG https://pflag.org/glossary/** 



### Vocabulary List: Plain Language Cancer Terms

Here are a few words and phrases that should be avoided and recommended explanations to use instead when communicating with audiences that don't have a background in cancer research and cancer care.

Jargon	Plain Language Definition
Benign	Noncancerous, not cancerous
Carcinoma	Cancer that forms in skin or tissues that line the internal organs
Chemotherapy	Using drugs to kill cancer
In situ	Cancers that remain in place and have not spread to nearby tissue
Leukemia	Cancer of bone marrow and blood
Lymphoma	Cancer that begins in immune system cells
Malignant	Cancerous
Oncology	The study of cancer
Radiation therapy	Treatment of cancer using high-energy x-rays
Sarcoma	Fat, muscle, and cartilage cancer



### Vocabulary List: Plain Language Research Terms

Here are a few words and phrases that should be avoided, and recommendations of what to use when communicating with audiences that don't have a background in research and clinical trials.

Jargon	Plain Language Definition
Case study	A study following/observing a single individual
Clinical trial	Research study involving real patients
Control group	Group of people in a study that do not receive treatment being studied
Dissemination	Communicating findings of a research study
Experimental group	Group of people in a study receiving the treatment being studied
Methodology	How research is done
Outcome measures	Measurement of the effects of treatment
Placebo	Fake treatment with no effect
Protocol	Plan for a piece of research
Randomized Control Trial (RCT)	Study comparing the group receiving treatment and the group receiving no treatment

For comprehensive dictionaries of cancer and research terms, review the NCI's Cancer Dictionary at\_https://www.cancer.gov/publications/dictionaries/cancer-terms

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### **Resources and How to Learn More**

Federal Plain Language Guidelines: The Plain Language Action and Information Network (PLAIN) developed this guide in 2011 to provide federal employees with guidance on strategies for communicating clearly to Citizens and effectively delivering information in an understandable way. <u>https://www.plainlanguage.gov/media/FederalPLGuidelines.pdf</u>

Making Data Talk NCI guide: This guide from the U.S. Department of Health and Human Services provides an overview of the main points contained in the book Making Data Talk: Communicating Public health Data to the Public, Policy Makers, and the Press in an effort to help you communicate quantitative data in ways lay audiences can understand. https://www.cancer.gov/publications/health-communication/making-data-talk.pdf

Making Health Communication Programs Work, NCI: This book is a revision of the original Making Health Communication Programs Work, developed by the Office of Cancer Communications (now the Office of Communications) of the National Cancer Institute and offers guidance on effectively planning communication programs and effectively communicating information about health. https://www.cancer.gov/publications/health-communication/pink-book.pdf

National Library of Medicine – Readability of Patient Education Materials on the American Association for Surgery of Trauma Website Study: This study evaluated the readability of a recognized source of expert content (the American Association for Surgery of Trauma AAST's online patient education materials); the study offers guidance relevant to cancer researchers for improving the readability of educational materials for patients and community members. <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4139691/</u>

NCI Cancer Dictionary: This official National Cancer Institute Dictionary f Cancer Terms features over 9,000 terms related to cancer and medicine with proper pronunciation and definitions to use in place of jargon. <u>https://www.cancer.gov/publications/dictionaries/cancer-terms</u>

Plain Language Healthcare Resources: Link to resources from the Plain Language Action and Information Network (PLAIN), which includes links to useful health literacy tools, guidance on creating understandable health education materials, and other health literacy resources. https://www.plainlanguage.gov/resources/content-types/healthcare/

National Library of Medicine – Plain language communication as a priority competency for medical professionals in a globalized world: A report highlighting the impact of the international movement of goods, people, and ideas on patient-provider communication in medical training and practice and how the implementation of plain language communication training for medical professionals as a core competency can mitigate the impact of globalization, which creates challenges with regard to patient-provider communication. <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6044302/</u>



### **Contact the CHECoE Team for Next Steps**

If you're interested in any services, would like to discuss other approaches and options, or wish to collaborate with the CHECoE team, complete our interest form <u>here</u> or contact us at <u>outreach@cinj.rutgers.edu</u> to start a conversation!

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