

Clinical Trials Outreach for Latinos: *Program Replication Manual*



ABOUT THIS MANUAL

The Clinical Trials Outreach for Latinos (CTOL) Program Replication Manual is a step-by-step instructional and resource guide to help your group:

- Learn about clinical trials and the need for outreach among minorities;
- Start clinical trials outreach activities in your organization;
- Adapt outreach materials and evaluations to your organizational needs; and
- Increase the number of Latinos who participate in clinical trials and biospecimen donation in your community!

The CTOL program and manual was developed by the Institute for Health Promotion Research (IHPR) at The University of Texas Health Science Center at San Antonio through two projects funded by the National Cancer Institute (NCI). Those projects are *Redes En Acción: The National Latino Cancer Research Network* (Grant No. 3 U54 CA153511) and the *Region 4 Transdisciplinary Geographic Management Program (GMaP)* program, which is building a synergistic network of investigators in basic, clinical, population- and community-based research to eliminate cancer health disparities. The Region 4 GMaP project has a sister project, *Minority Biospecimen/Biobanking Geographic Management Program (BMaP)*, based at New Mexico State University.

For more information about replicating this program, email us at IHPR@uthscsa.edu.

CITE THIS MANUAL

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We would like to thank the organizations listed in our resource directory for welcoming us into their organizations and meetings to conduct this educational module.

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We're glad you're ready to learn more about clinical trials outreach for Latinos!

We created the Clinical Trials Outreach for Latinos (CTOL) Program Replication Manual to give you tips, resources, and other help to incorporate these activities in your organization.

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Section 1:

Clinical Trials Outreach for Latinos (CTOL)



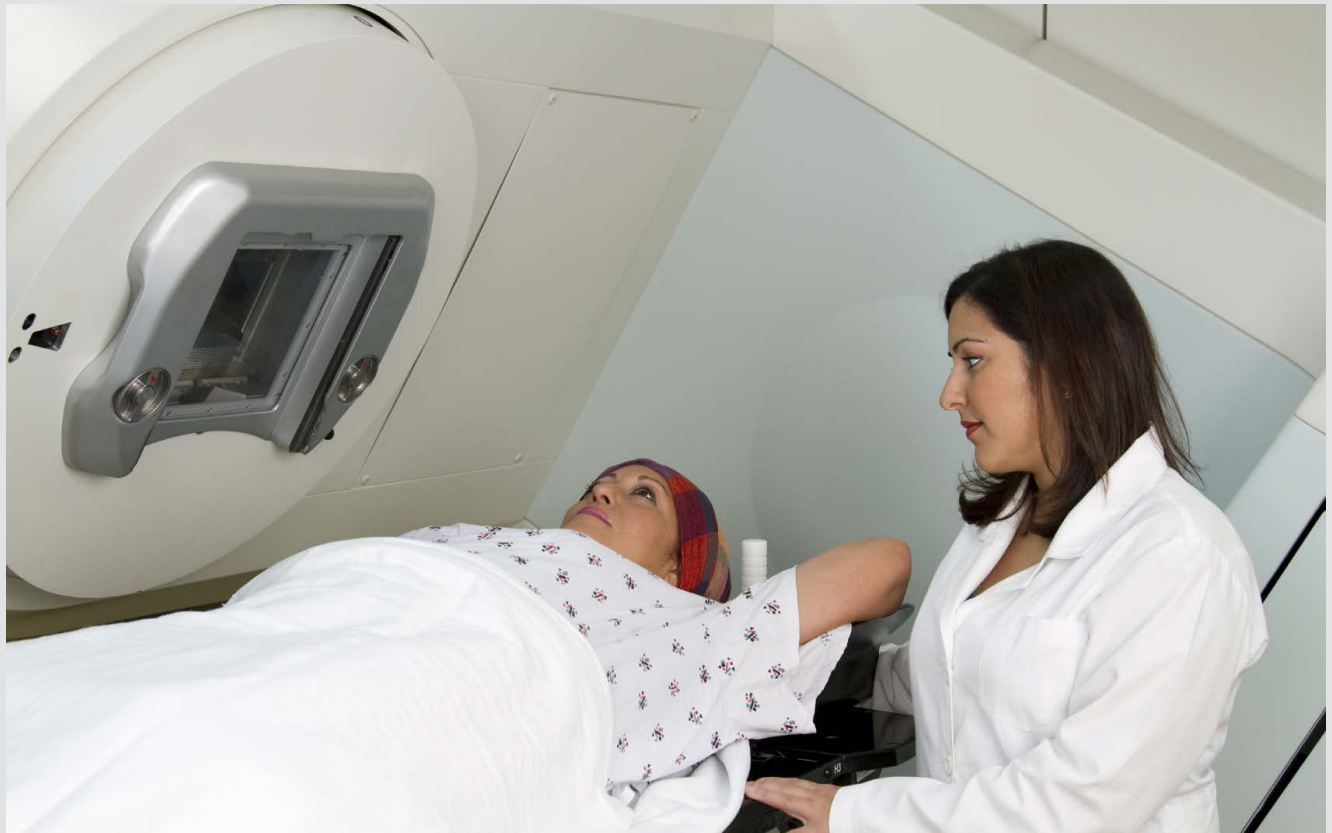


Cancer Health Disparities

The National Cancer Institute defines “cancer health disparities” as “differences in the incidence, prevalence, mortality, and burden of cancer and related adverse health conditions that exist among specific population groups in the United States.”

For instance, Latinos face different rates of certain cancers than non-Latino Whites.

You can learn more about cancer health disparities by visiting the NCI’s website at <http://crchd.cancer.gov/disparities/defined.html>.



Why is CTOL needed?

CTOL is needed because Latinos face many cancer health disparities.

Latinos have higher incidence rates of liver, cervical, stomach, and gallbladder cancers than the general population.

And because of socioeconomic and healthcare access issues—language, cultural myths, less education and income, and a lack of a primary care doctor or health insurance, etc.—Latinos often forego or delay receiving timely healthcare services for illnesses and injuries, putting them at risk for suffering worse health-related outcomes.

Latinos also lack participation in cancer clinical trials.

Only about 5 percent of Latinos participate in National Cancer Institute (NCI) cancer clinical trials, statistics show.

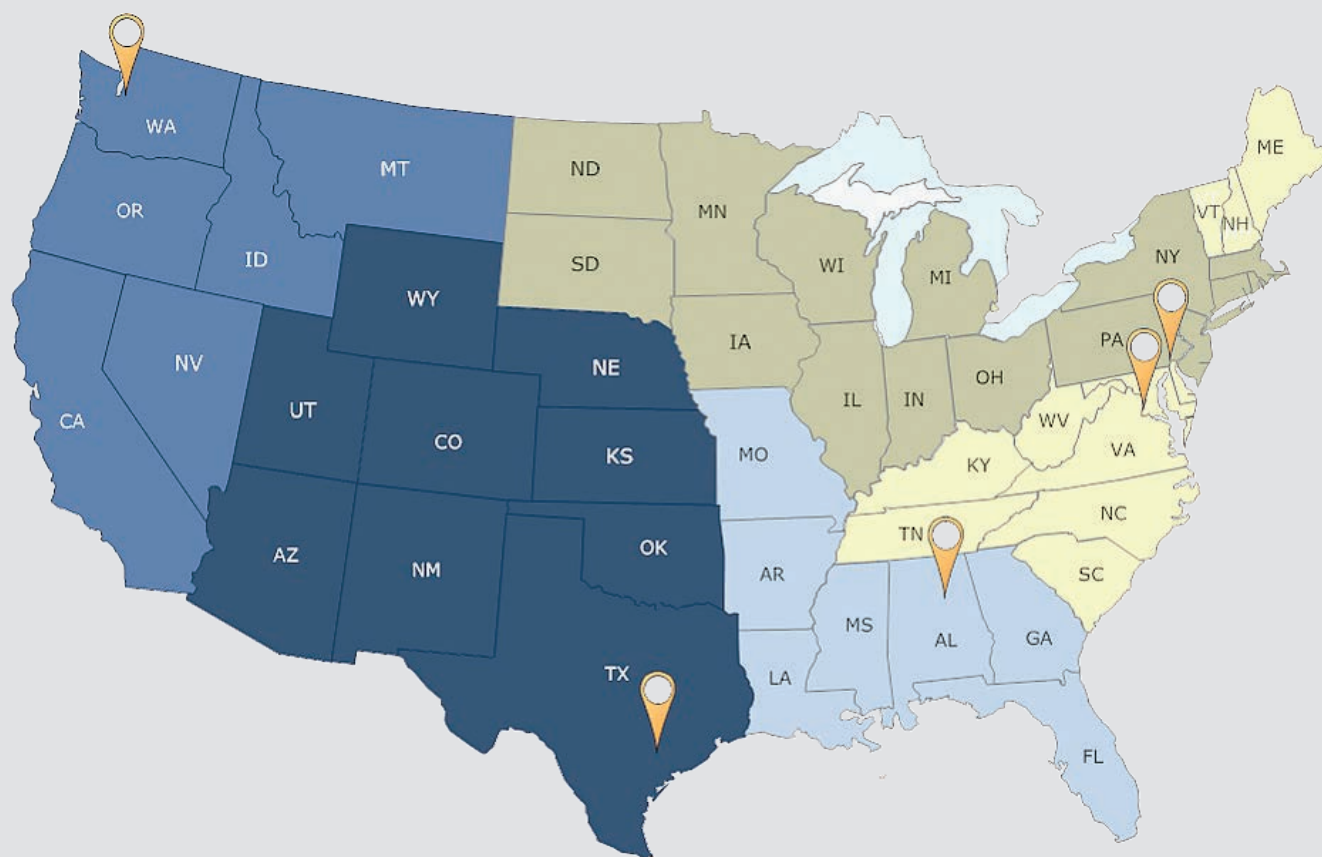
There is a great need for increased participation in clinical trials, as well as for donations of biospecimens—materials from the human body (skin, hair, and fluids such as blood, urine, or saliva) that can help researchers look for ways to prevent or treat cancer.

Why participate in clinical trials?

Most of today's best cancer treatments are based on what we learned from past clinical trials.

Progress made through clinical trials is helping cancer patients live longer, healthier lives.

The more people join clinical trials, the faster we can find better cancer treatments and prevention options and increase the survival rate.



For more information on GMaP visit <http://crchd.cancer.gov/inp/gmap-overview.html>

Our CTOL Program

We created an educational, culturally infused outreach program to empower Latinos to decide to participate in clinical trials and donate biospecimens.

Our program, called Clinical Trials Outreach for Latinos (CTOL), was based on results from our work through the Region 4 Transdisciplinary Geographic Management of Cancer Health Disparities Program (GMaP) and Minority Biospecimen/Biobanking Geographic Management Program (BMaP) projects, which cover Texas, Arizona, Colorado, Kansas, New Mexico, Oklahoma, Nebraska, Wyoming and Utah.

We developed the program after we found that many people at various cancer facilities across our region were eligible to participate in clinical trials—but they weren't joining them.

We also found a need to increase the diversity of participants in trials.

CTOL Program Purpose:

- Increase Latinos' informed decision-making about joining clinical trials and donating biospecimens
- Highlight the importance of participating in trials and donating biospecimens
- Discuss risks and benefits of participation
- Provide resources for available local and national trials and biobanks

Section 2:

How to Start and Implement CTOL in Your Organization





We recommend you take four steps to adapt the CTOL Educational Module to meet your organizational needs:

1. Download the CTOL Educational Module PowerPoint Presentation
2. Train Community Health Educators or Community Health Workers
3. Build your own community resource directory
4. Recruit organizations for support

The CTOL Educational Module

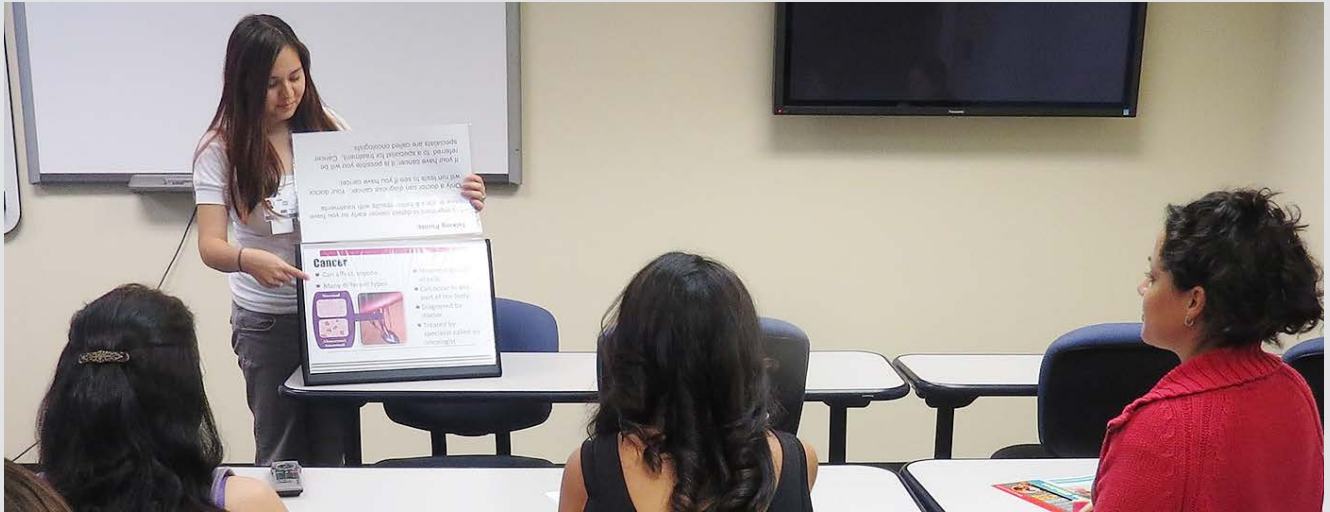
Our CTOL program offers an educational module to teach the community about clinical trials, their purpose, and benefits.

Content for the module was primarily derived from National Cancer Institute publications ([references](#)) and developed at a sixth-grade reading level in both [English](#) and [Spanish](#).

Educational module content includes:

- Latino cancer and clinical trial participation statistics
- Trial phases
- Treatment and prevention trials
- Control and intervention groups
- Placebos
- Consent forms
- Risks and benefits of trial participation
- Resources/How to participate in trials
- Biospecimen donation and biobanks

The content is presentable using PowerPoint slides or flipcharts.



Adapting the CTOL Educational Module

Step 1: Download Presentation

We recommend you take four steps to adapt the CTOL Educational Module:

Download the CTOL Educational Module PowerPoint Presentation in **English** or **Spanish**.

For the editable PowerPoint presentation file, email us at ihpr@uthscsa.edu.

You can use this template or create your own. If you use this presentation, be sure to:

- Insert your institutional logo (slides 1, 2, 24)
- Include cancer statistics for your county/ location and population (slide 4)
- Include the contact information for your local cancer center (slide 21)

Tips for Presenting the CTOL Educational Module:

- Use community health workers (CHWs) or educators to present the educational module
- Allow for 30 minutes to present, but adjust for shorter/longer time frames
- “Piggyback” presentations into a regularly scheduled group meeting
- Prepare for presentations in both English and Spanish

Tips for Adapting the Presentation:

- **Language:** The module was developed at a 6th grade reading level and is available in English and Spanish. Be prepared to revise it to accommodate for regional language differences (specific Hispanic subgroups) and to modify reading levels as needed for your target audience.
- **Cultural Needs:** This module is geared towards a Hispanic/Latino audience, it can be easily adapted for other minority audiences if needed.
- **Electronic Equipment vs. Flipcharts:** Consider the group’s resources and space when conducting the module. A flipchart may be more appropriate for smaller audiences.



Adapting the CTOL Educational Module

Step 2: Train Workers

Community health workers (CHWs) and community health educators (CHEs) are the bridge between the community and the medical/public health field. They are experts at providing health education and linking the community with available resources.

We recommend at least one week of training to

- Get familiar with the educational module
- Practice delivering the module in English and Spanish (at least 5 times in each language or until the material has been mastered)
- Shadow an experienced presenter, if needed
- Conduct a final test presentation for the research team to prove mastery of the module and its content

CHE/CHW Qualities

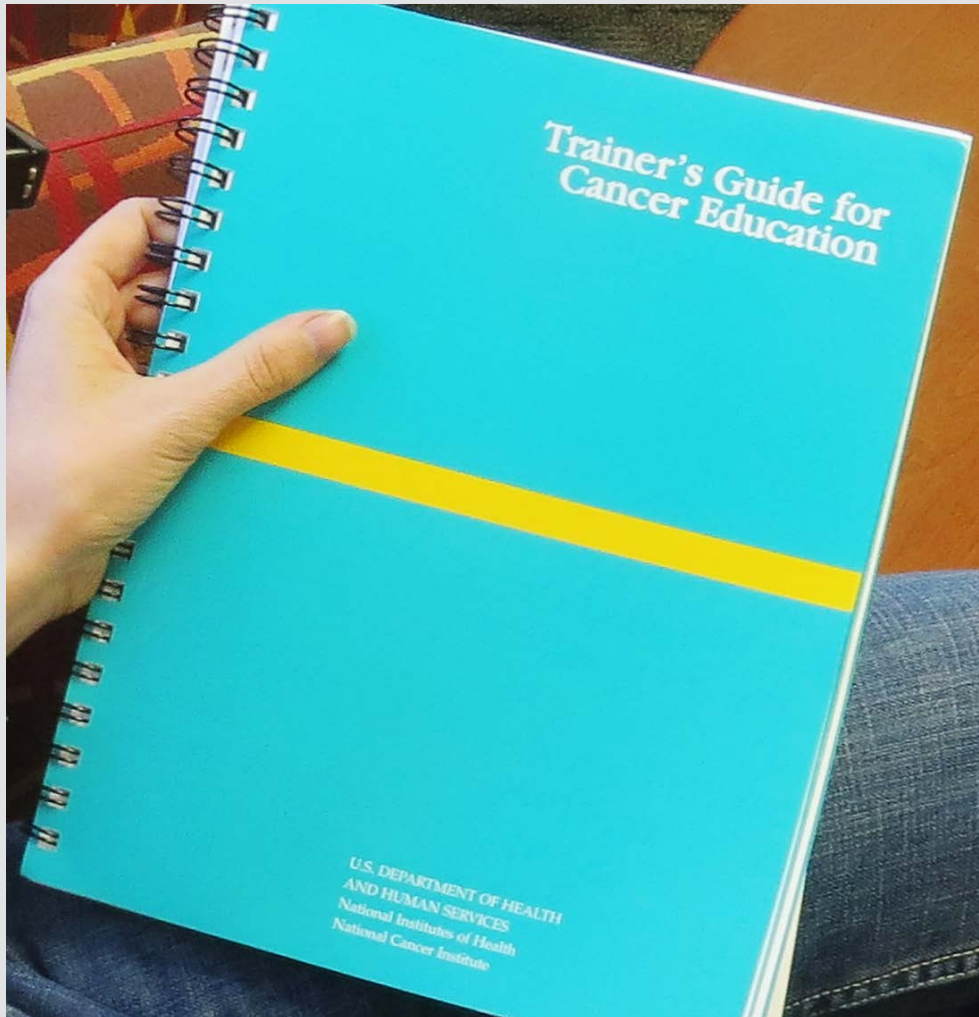
CHEs/CHWs are a very special group of professionals. They must possess certain professional skills as well as various personal characteristics.

Professional:

- Responsible
- Organized
- Resourceful
- Reliable
- Positive-minded
- Team player

Personal:

- Caring
- Friendly
- Warm
- Trustworthy
- Patient
- Dedicated



Adapting the CTOL Educational Module

Step 2: Train Workers

During the training period, CHEs/CHWs also should become familiar with NCI training resources to expand their knowledge of clinical trials and biospecimens.

NCI Training Resources:

[Cancer Clinical Trials: A Resource Guide for Outreach, Education, and Advocacy](#)

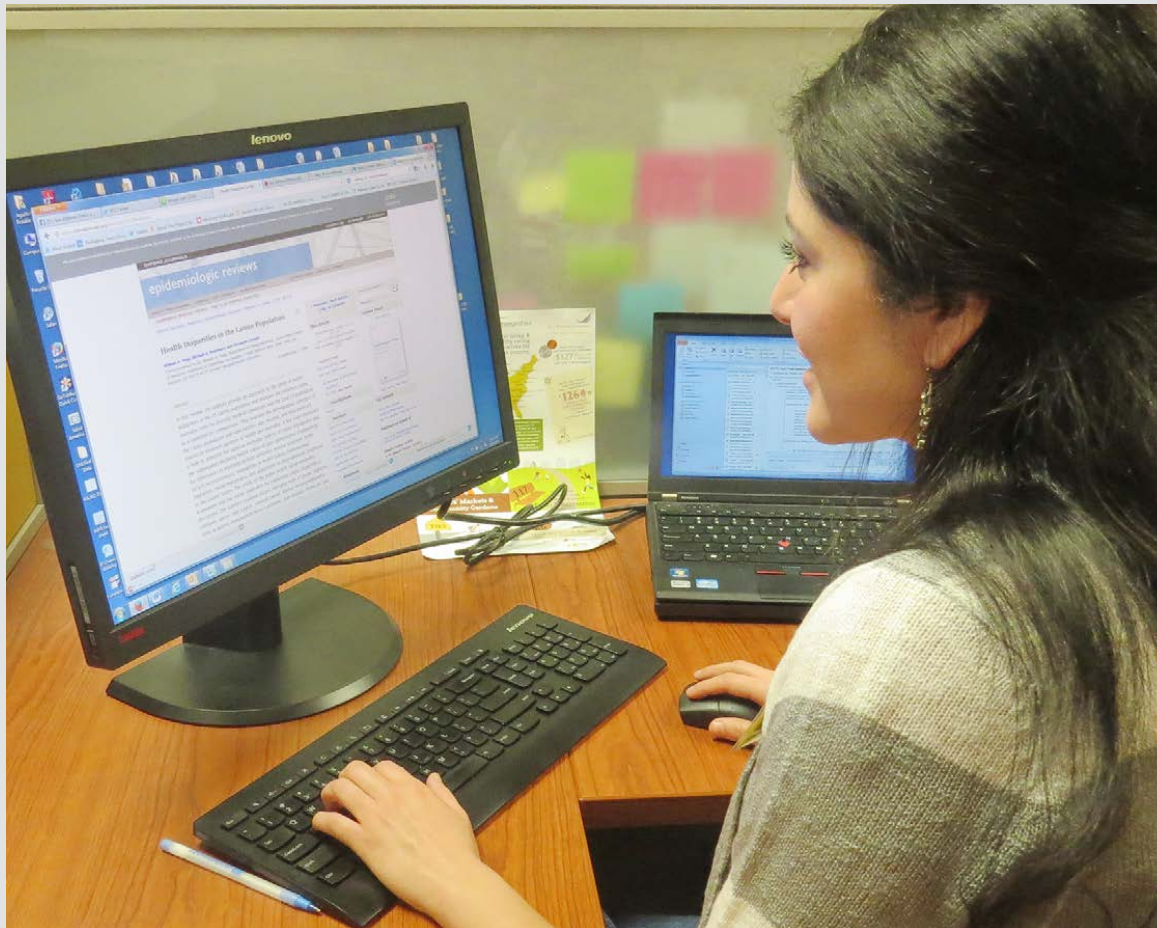
[Cancer Clinical Trials: The In-Depth Program](#)

[Cancer Clinical Trials: The Basic Workbook](#)

[Trainer's Guide for Cancer Education](#)

[Making Health Communication Programs Work and a Trainer's Guide for Cancer Education](#)

[What are Biospecimens and Biorepositories, NCI Biorepositories and Biospecimen Research Branch \(BBRB\)](#)



Adapting the CTOL Educational Module

Step 3: Develop a Community Resource Directory

As your program develops, we recommend you develop a community resource directory. This directory should include a listing of existing organizations or programs in your community to whom you may want to deliver the educational module. The directory should include the names of the organizations, contact persons, addresses, telephone numbers, e-mails and a brief description of the organization.

The directory can be instrumental in helping you identify, track, and remain in contact with individuals, groups, and organizations.

As an example, check out our [CTOL program resource directory](#).

Tips for Building a Directory:

- Identify an established community directory in your community
- Create your own directory by searching the Internet, contacting local community organizations (such as the local affiliates of the American Cancer Society, Susan G. Komen for the Cure, The United Way), or your existing contacts
- Review collected resources for relevant information and relevant organizations



Adapting the CTOL Educational Module

Step 4: Recruit Support

After adapting your presentation/materials, training CHEs/CHWs and putting together your resource directory, you are ready to start contacting partners to schedule presentations.

You may want to begin by contacting people you have worked with in the past.

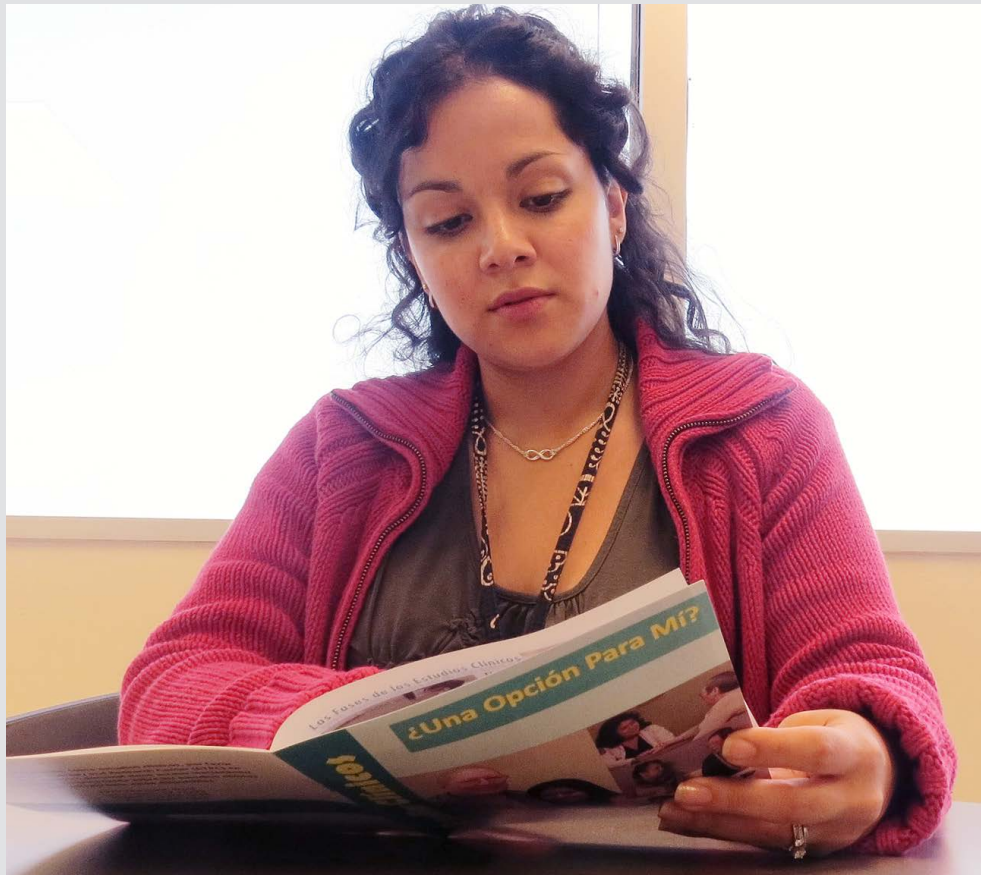
Tips for Contacting Organizations:

- Contact each group directly
- Introduce yourself and the program either through phone, e-mail, or direct contact.
- Offer to follow up in person
- Develop partnership agreements so that groups can then help you promote the program with other contacts they may know
- Collaborate and develop a flyer to promote the event
- Realize that multiple forms of contact may be required

Section 3:

Clinical Trial and Biospecimen Resources





CTOL Take-Home Resources

When you conduct educational presentations, hand out resource materials for participants to take home and review further. This will help reinforce the message and educational component.

Think about preparing a flyer with information about enrolling in trials locally. Include your local cancer facility's name, address, and number to call to find out more about existing clinical trials at the facility.

You also could create new clinical trial and biospecimen educational materials or use existing resources.

Our CTOL Take-Home Materials

- [Clinical Trials: An Option for Me?](#)
- [Estudios Clínicos: ¿Una Opción Para Mi?](#)
- [Biospecimen Flyer: English](#)
- [Biospecimen Flyer: Spanish](#)

NCI Take-Home Materials

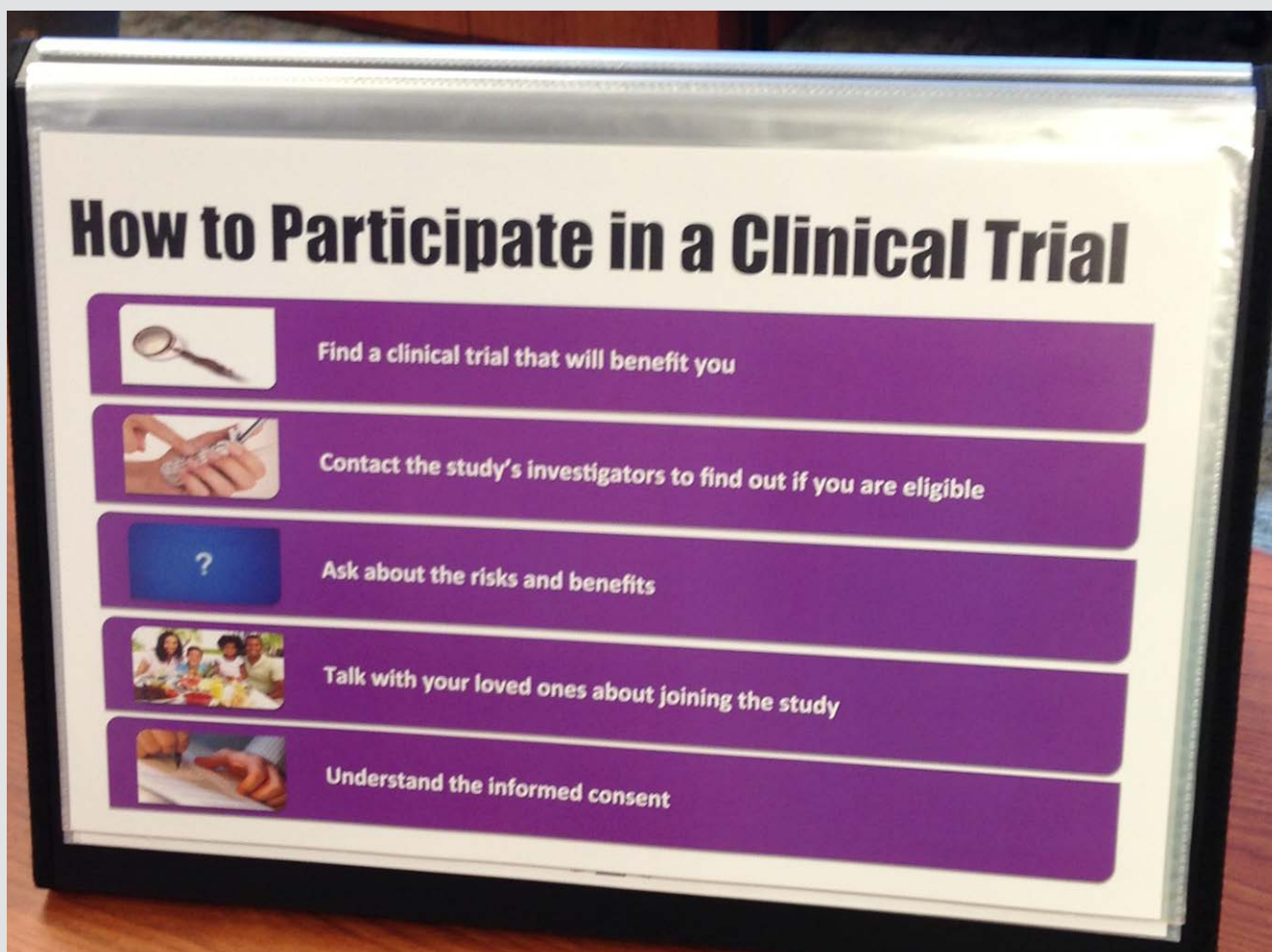
You can order NCI publications on clinical trials, biospecimens and other research [here](#) or call to order at 1-800-422-6237. Materials include:

- **Taking Part in Cancer Treatment Research Studies**
- **If You Want To Find Ways to Prevent Cancer... Learn About Prevention Clinical Trials (available in Spanish)**
- **Donating Tissue for Cancer Research: Biospecimens and Biorepositories**
- **How Can We Help? National Cancer Institute Points of Access Bookmark/¿En qué podemos ayudarle?: Marcador de libros de las vías acceso a la información del Instituto Nacional del Cáncer**

Section 4:

Program Data Collection and Evaluation





Data Collection

Every program should have a system for collecting data that reflects the quality and quantity of services provided.

For our CTOL program, we collected participant demographic information and assessed participants' knowledge on the topic.

A pre-evaluation form can assess what the participant may already know before the presentation is delivered. A post-evaluation form can gather information of what the audience might have learned after the presentation.

You can create your own forms or adapt the templates and methods provided.



Demographic sheet

The demographic sheet asks participants un-identifying demographic information.

This information is important in identifying the audience/population you are serving.

The form contains fields for the participants:

- **Initials**
- **Zip code**
- **Gender**
- **Age**
- **Race**
- **Ethnicity**
- **Education level**

Download Demographic Sheet Form Template in [English](#).

Download Demographic Sheet Form Template in [Spanish](#).



Evaluation Forms

For our CTOL project, we used pre- and post-evaluation forms to measure the change from what participants knew about clinical trials and biospecimens at the beginning of each educational presentation and then at the end.

Pre-Evaluation Form:

- 6 questions
- Completed before the start of the presentation
- Download Pre-Evaluation Form: [English](#) or [Spanish](#)

Post-Evaluation Form:

- 8 questions
- Completed at the end of the presentation
- Download Post-Evaluation Form: [English](#) or [Spanish](#)

After collecting the post-evaluation forms, make sure to leave time to answer any additional questions.

Section 5:

CTOL Templates





Use Our Templates

CTOL Educational Modules Templates

- [English](#)
- [Spanish](#)

CTOL Data Collection Forms

Demographic Sheet:

- [English Template](#)
- [Spanish Template](#)

Pre-Evaluation:

- [English Template](#)
- [Spanish Template](#)

Post-Evaluation:

- [English Template](#)
- [Spanish Template](#)

CTOL Take-Home Resources

- [Clinical Trials: An Option for Me?](#)
- [Estudios Clínicos: ¿Una Opción Para Mí?](#)
- [Biospecimen Flyer: English](#)
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