

# Talking About Research

Imagine: You talk with a patient about research. They tell you what they think or have questions. What might you share about what you know about research?

Client	Client's Opinion or Question	Possible Ideas to Talk About With the Client
Linda	"That sounds like too much trouble. It's not worth my time. "	
Dejuan	"I don't trust the hospital with my DNA. They might put it on the internet!"	
Lupe	"Nobody's ever asked me to be in a study. What do I have to do?"	
Rita	"That sounds dangerous. How do I know it's safe?"	
Jorge	"What kind of information will they need? I don't want anybody knowing where I live or calling my house."	
Charles	"I am sure there are plenty of other people who want to do this study. They don't need me."	

# The Chewing Gum Study

✎ Dr. Jones wants your advice before she submits the proposal to the IRB. Write down at least 5 problems with this study.



Dr. Jones is doing a study on chewing gum. She thinks gum with a special chemical, Defghi, might help people lose weight if they chew it enough. Here's her plan:

- People chew gum for 4 hours a day
  - They must chew it even if they are in pain
  - People will weigh themselves on a scale at home and keep track and tell Dr. Jones
  - People should estimate at the end of every day how many hours they chewed gum
  - People can eat whatever they want
  - Anyone who wants to join the study can be in it
  - They get free chewing gum for six months. They could lose up to five pounds
  - The medicine in the gum hasn't been tested on animals yet

There is no compensation. They will need to come to the

university about 20 times in 6 months.

# Getting the Right Participants

Your research team wants to learn about depression. Participants must be women who:

- Live in Chicago
- Are at least 24 years old and younger than 50 by the end of the year
- Have been diagnosed with depression by a doctor

## Who can participate? Who can't?



**Teresa** lives in the city. She has never talked to her doctor about depression. Her Community Health Worker thinks the study would be good for Teresa because she has low energy.

- ☐ Yes
- ☐ No



**Candace** grew up in the city and now lives in a nearby suburb. She will be 50 next year. She was diagnosed with depression after she had her last child. Her friend is a Community Health Worker. She thinks it's fine if Candace just says she lives in Chicago.

- ☐ Yes
- ☐ No



**Victoria** lives downtown. She's 37. She was diagnosed with depression 7 years ago. She uses diet and exercise to help manage it. She saw a sign on the bus about the study.

- ☐ Yes
- ☐ No



**Monica** is a waitress and in school to be a hairstylist. She was diagnosed with depression when she was a teenager. She will be 24 in January. She has lived in Chicago her whole life. Her friend enrolled in the study and told her about it.

- ☐ Yes
- ☐ No



Take a look at this sample flyer...What do you like? What could be better?  
Remember, the goal is to interest people in your community.

S.E.E.C. Study #1 , 5/31/12, V#4.0

CCTS Grant # UL1RR555555



## A Study About Your Opinion of Research Participation.

### The S.E.E.C. Study

Supporting Enrollment and Engagement in Clinical Research

**Research Description & Purpose:** Researchers at ABC Medical Center and University want to find ways find out reasons why African Americans and Hispanics, may or may not volunteer for clinical research studies. Research is always voluntary!

**Would the study be a good fit for me?** This study may be a good fit for you if:  
You Identify yourself as Hispanic or Latino  
You are 18 years or older

**What would happen if I took part in the study?** If you decide to take part in this research study, you would participate in a single group discussion for 2-3 hours. This study is NOT testing any drugs or other treatments.

Volunteers who take part in this research get a \$50 gift card to thank them for their time and travel.

**Where will research take place?:** This research will take place at Community Centers and churches in Chicago

**Contact Information:** To take part in the S.E.E.C. Study or to get more information, **please call 312-555-5555** or email [janedoe@abcuniversity.edu](mailto:janedoe@abcuniversity.edu)

**PI Name, department & address:** The principal researcher for this study is Jane Doe, MD, MPH at the ABC University at 123 S. Main St., 312-555-5555. Study IRB#: 2011-5555

**ABC University Medical Center and University**

# Getting All the Facts



## Story #1

Terri and her husband George have been married for 30 years. They have 3 children and 8 grandchildren. They both just retired. Unfortunately, Terri just found out she has a rare tumor in her brain.

The doctor told her about three choices:

1. She can do nothing. She can enjoy her life. She could live up to 2-3 more years.
2. She can take the usual medicine that doctors use for her tumor. She will have to spend a lot of time in the hospital and may feel badly. If it works, she might live 5-10 more years.
3. She can join a research study for a brand new medicine. She doesn't know if she will get the new medicine or the regular medicine (like the medicine in #2). It's an experimental double-blind study. If it works, the doctors hope it will shrink tumors completely and people won't have to stay in the hospital as long. If the new medicine is more effective, she would get it eventually if she didn't get it at first.

### Assignment:

Terri went home but didn't really understand what the doctor said. Terri asks her community health worker to explain the options again in a way that she can understand.

*How might you explain the choices to Terri? What questions would you still have for the doctor? Practice with your partner.*



## Story #2

Dana's son Charlie has autism. His doctor thinks their family would be perfect for a new study about how to support children with autism. He is the right age for the study.

In the study, the parents would take an 8 week class or read a series of books. They would keep a journal about what they learned from the classes or books. They would also be interviewed several times as would their children and observed as a family several times as well. The whole study would take about a year.

Participating in the study might help parents learn new strategies to help their children thrive in work and school.

### **Assignment:**

Dana gets nervous around doctors and asked you, her Community Health Worker, to explain how the study would work and the steps involved.

*How might you explain the study to Dana? What questions would you or Dana still have for the doctor? Practice with your partner.*