

# DBSA Consumer and Family Survey Center

Consumer Attitudes Towards  
Participation in Clinical Research  
Spring 2010

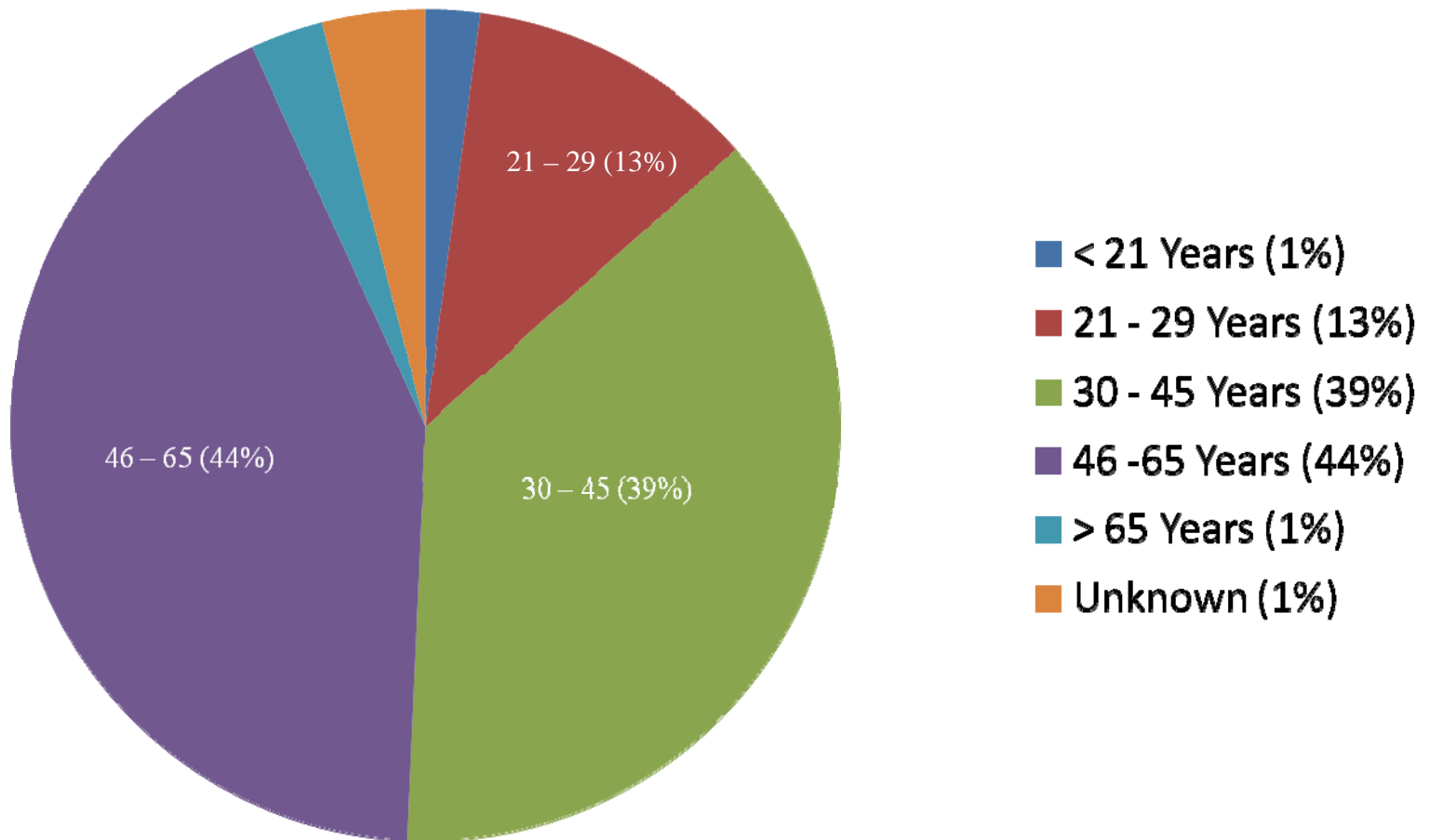
# Consumers Attitudes Towards Clinical Research

- Background – DBSA Consumer and Family Survey Center
  - Quarterly Web Based Survey: [www.dbsalliance.org](http://www.dbsalliance.org)
  - Subject Areas
    - Demographics/background
    - Participation consideration
    - Reasons to not participate
    - Reasons to participate
    - DNA and research

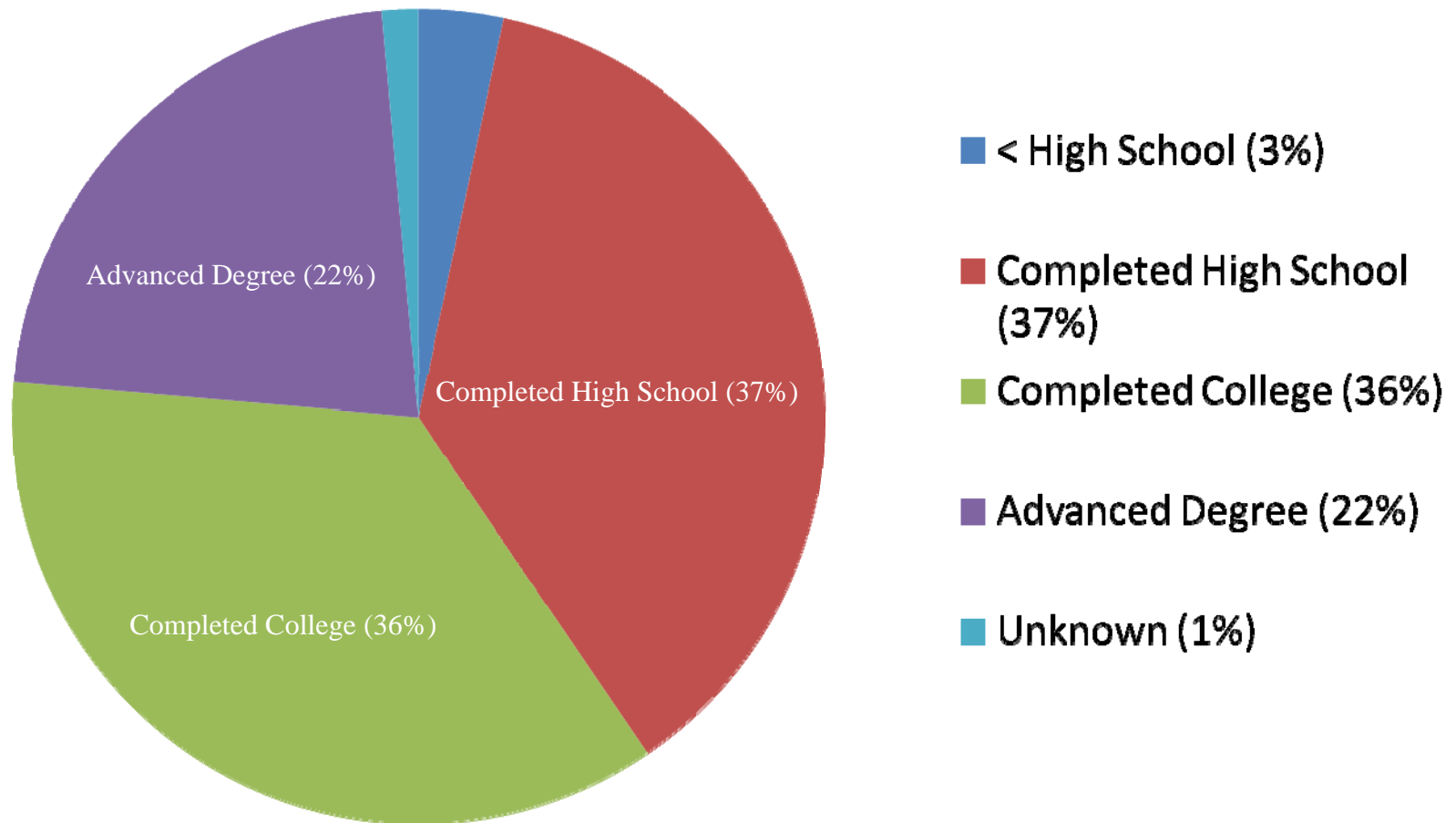
# Part 1: Demographics/Background

- Sample Size: 424 (open web based participation)
- Respondents: 81% Female; 89% Patient, 10% Family/Friend
- Diagnosis: 58% Bipolar, 30% Depression, 5% None
- Education: 37% Completed High School, 36% Completed College, 22% Advanced degree
- Age Range: (14 – 72 Years of age)
  - <21 (1%)
  - 21 – 29 (13%)
  - 30 – 45 (39%)
  - 46- 65 (44%)
  - >65 (1%)

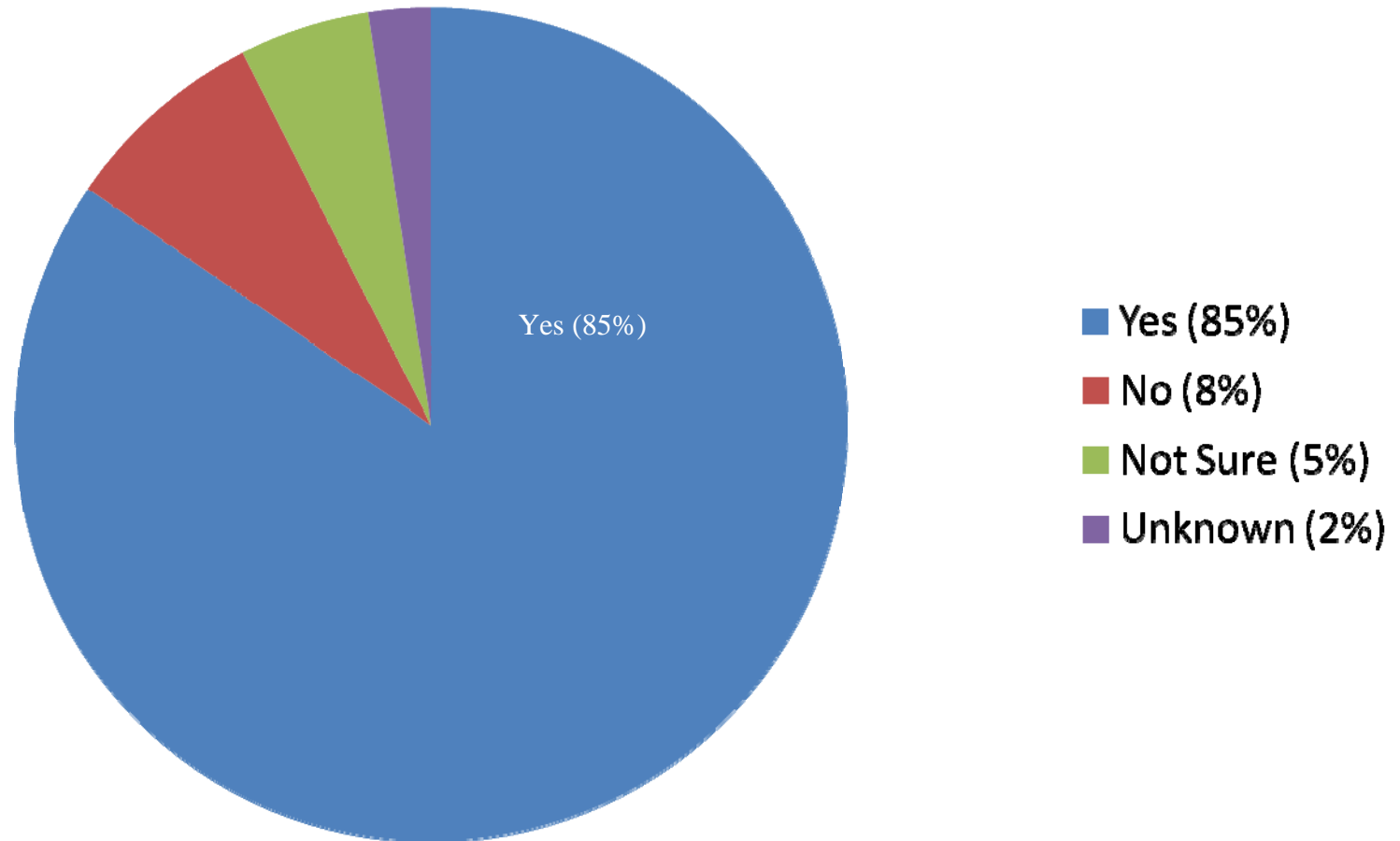
# Age Range



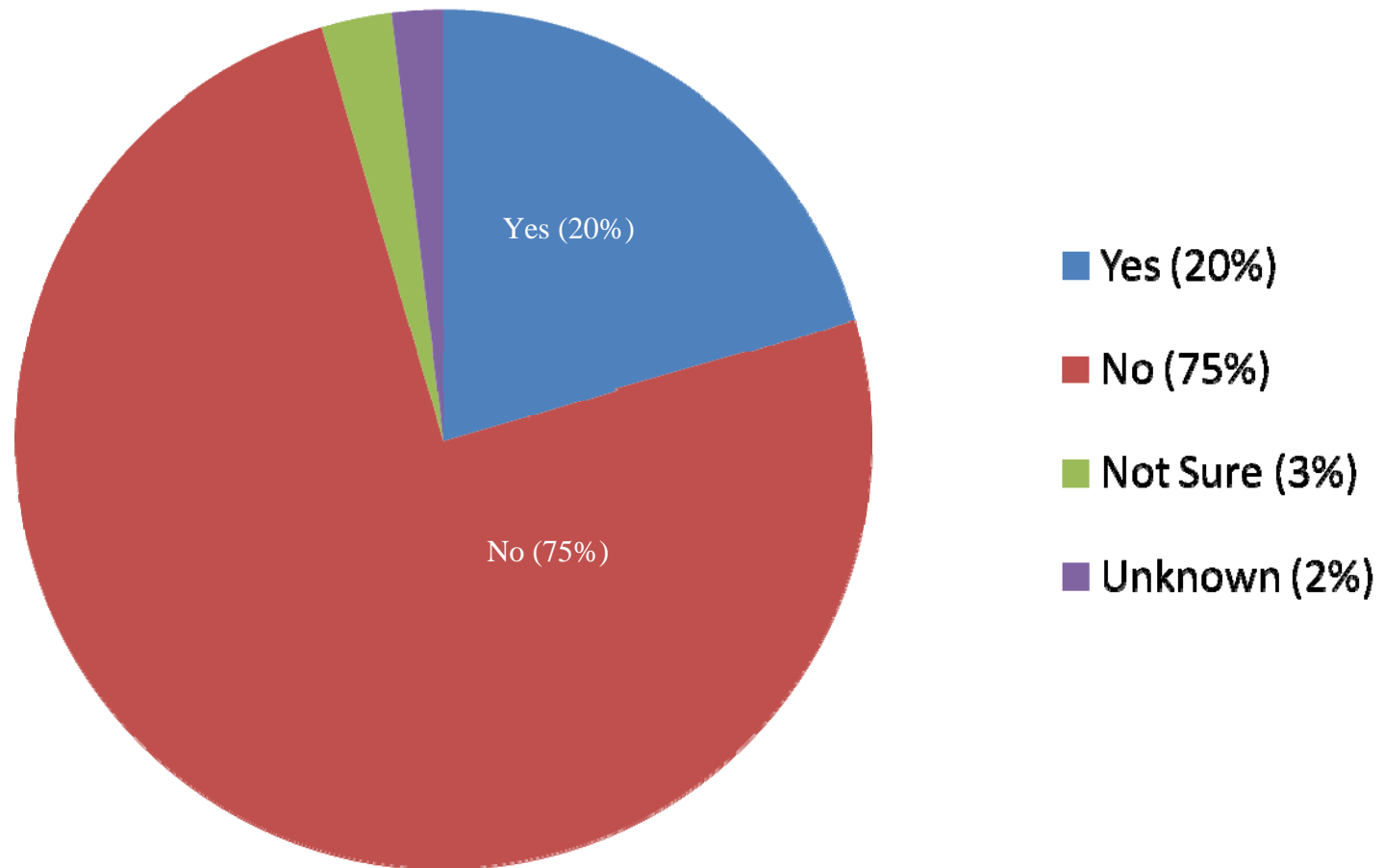
# Education



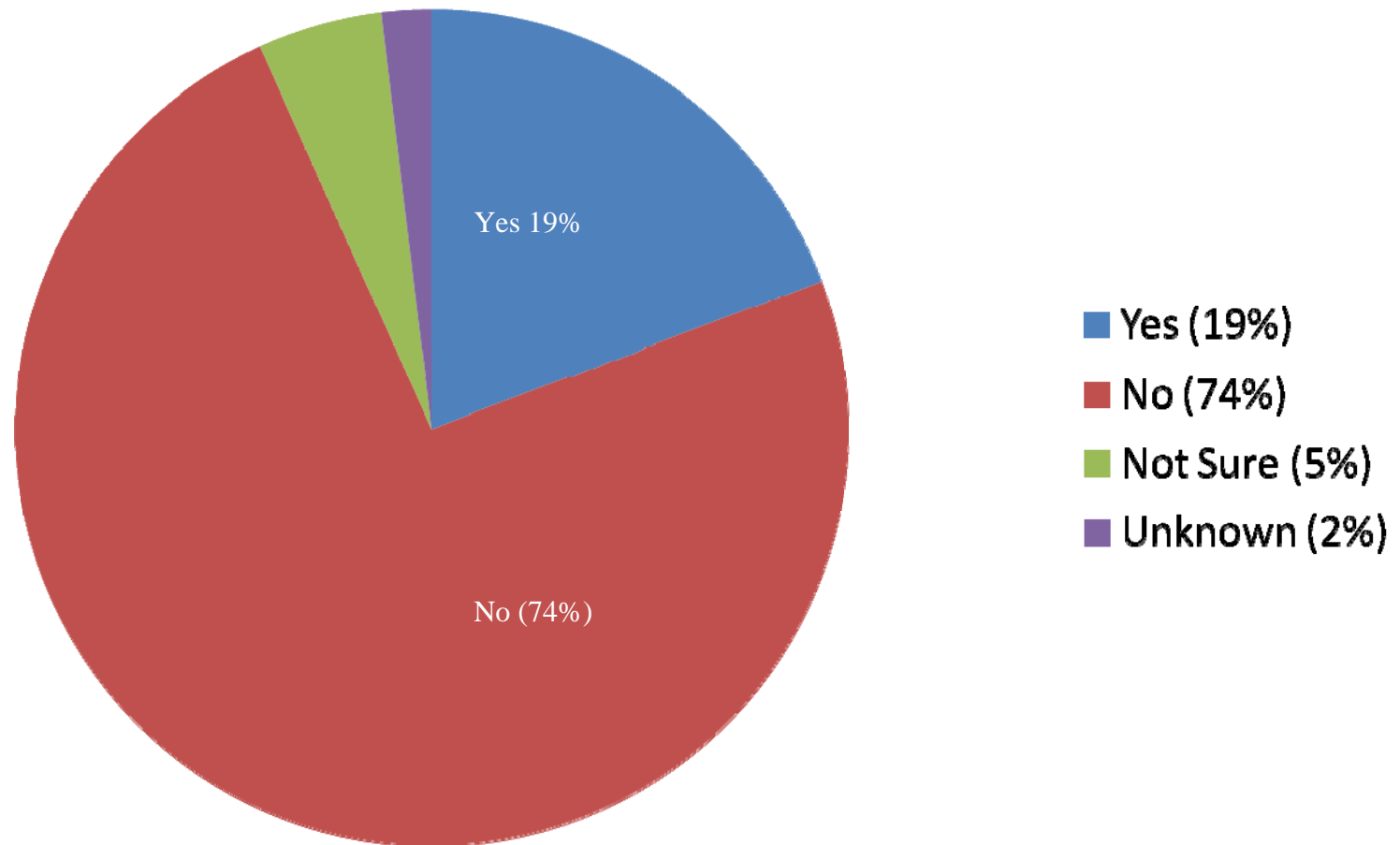
# Have you ever heard of clinical research?



Have you ever participated in a clinical research study, either for mental health or other health conditions?



Have you ever been referred, or recommended, to participate in a clinical research study?

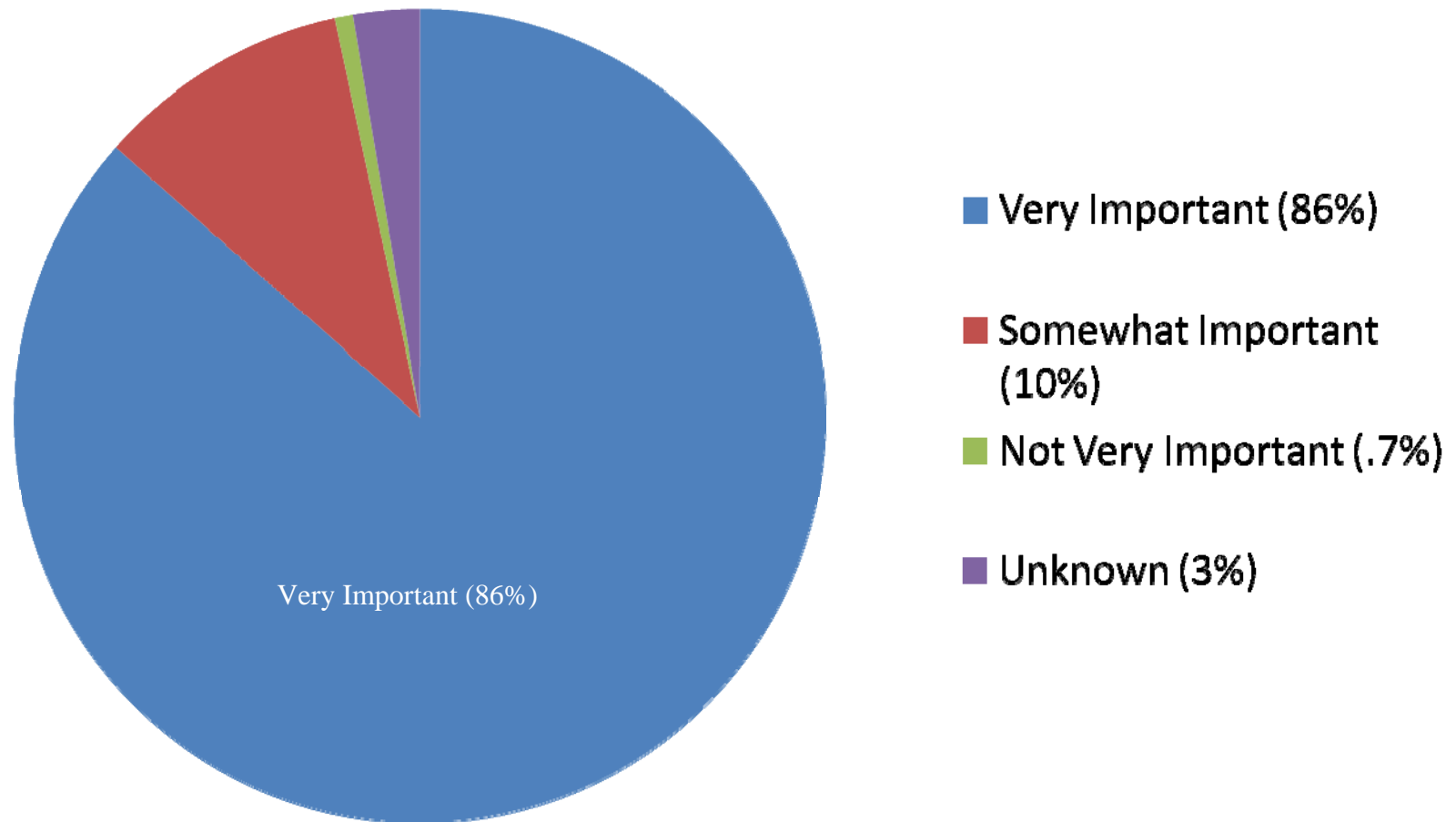




## **Part 2: Participation Consideration**

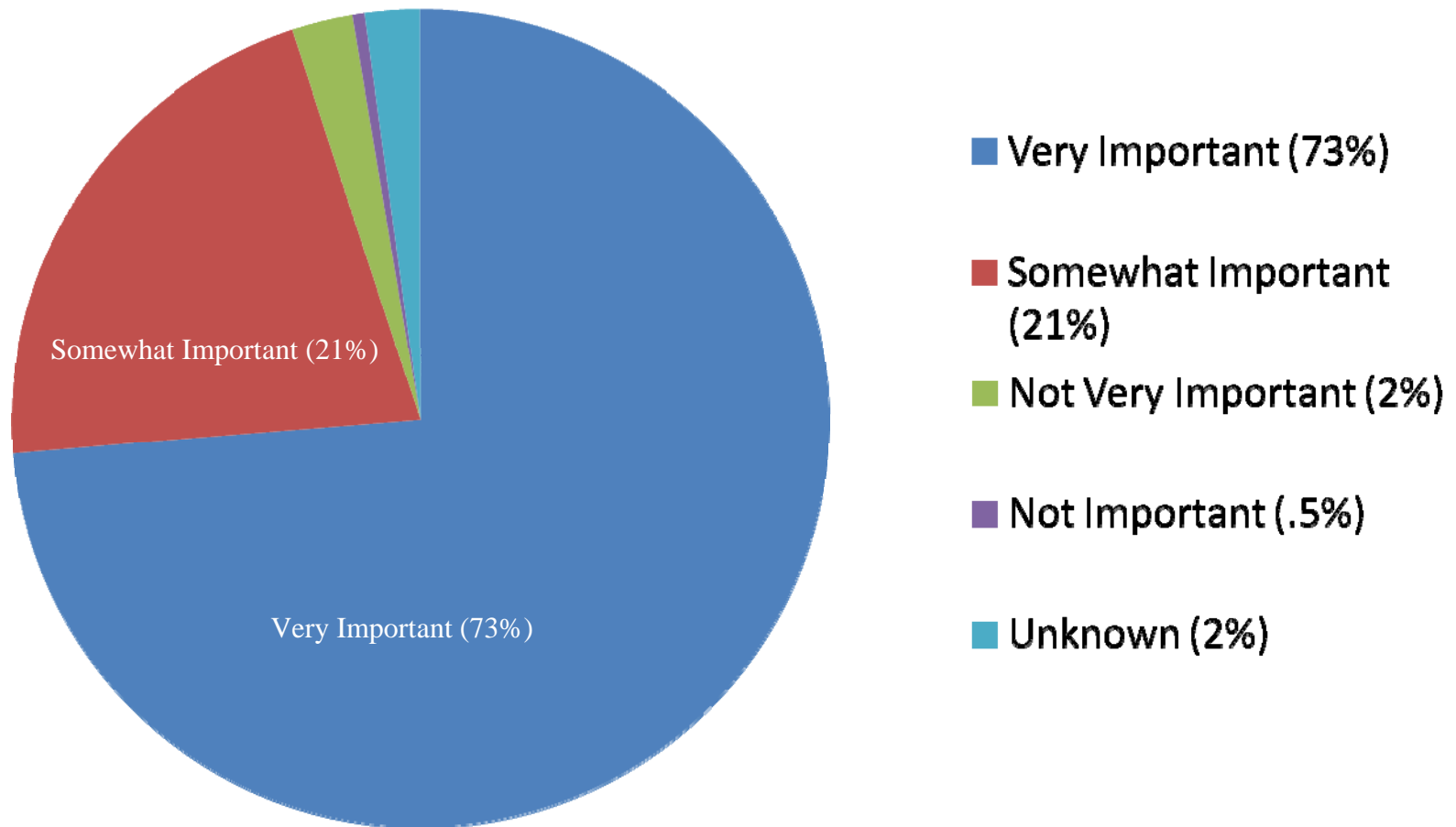
**What information would be important for you to have when thinking about participating in a clinical research study?**

# What to expect from participating in a clinical research study, including the advantages and disadvantages



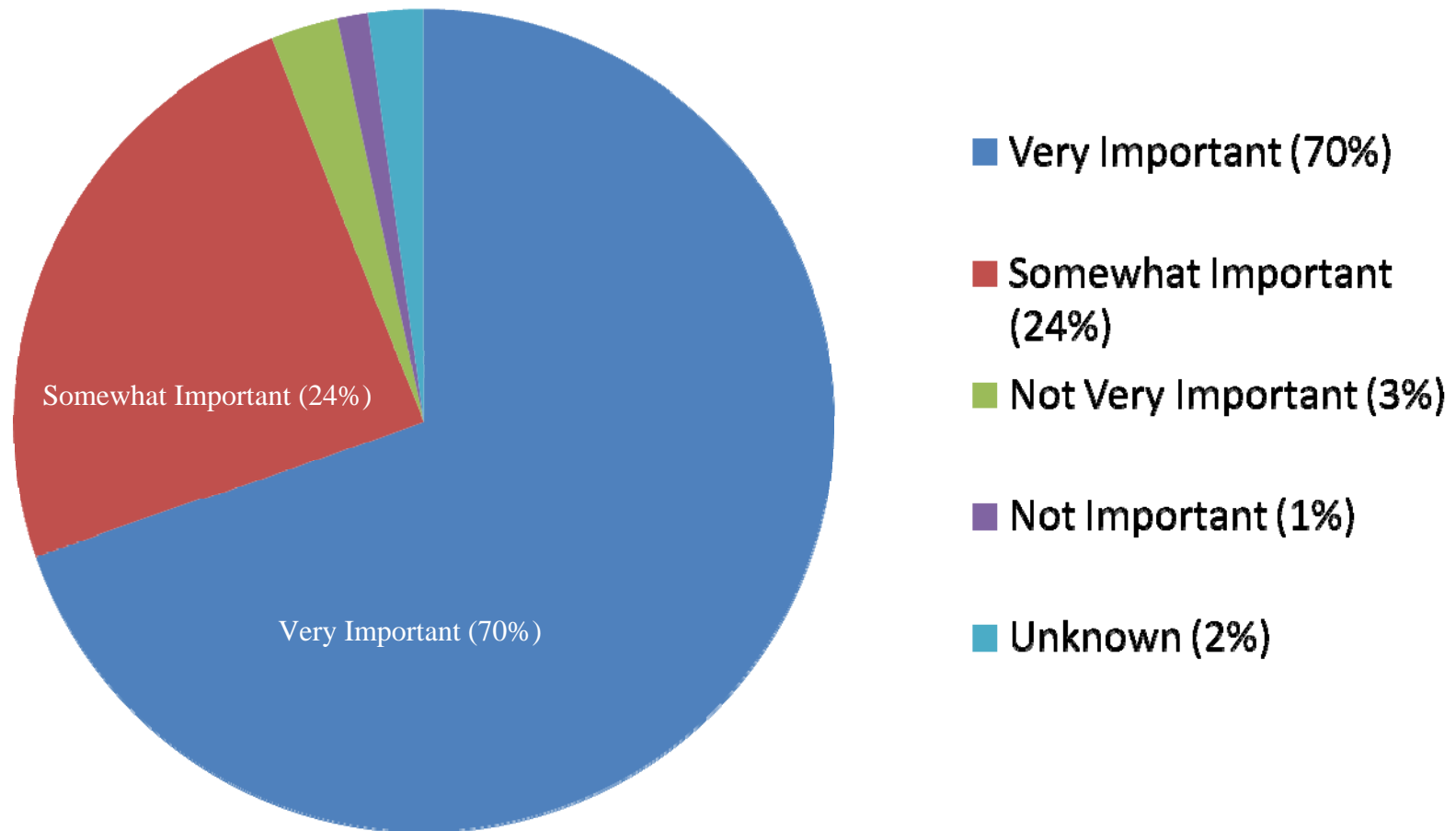
Very/Somewhat Important = 96%

# Brochures that clearly explain the research study



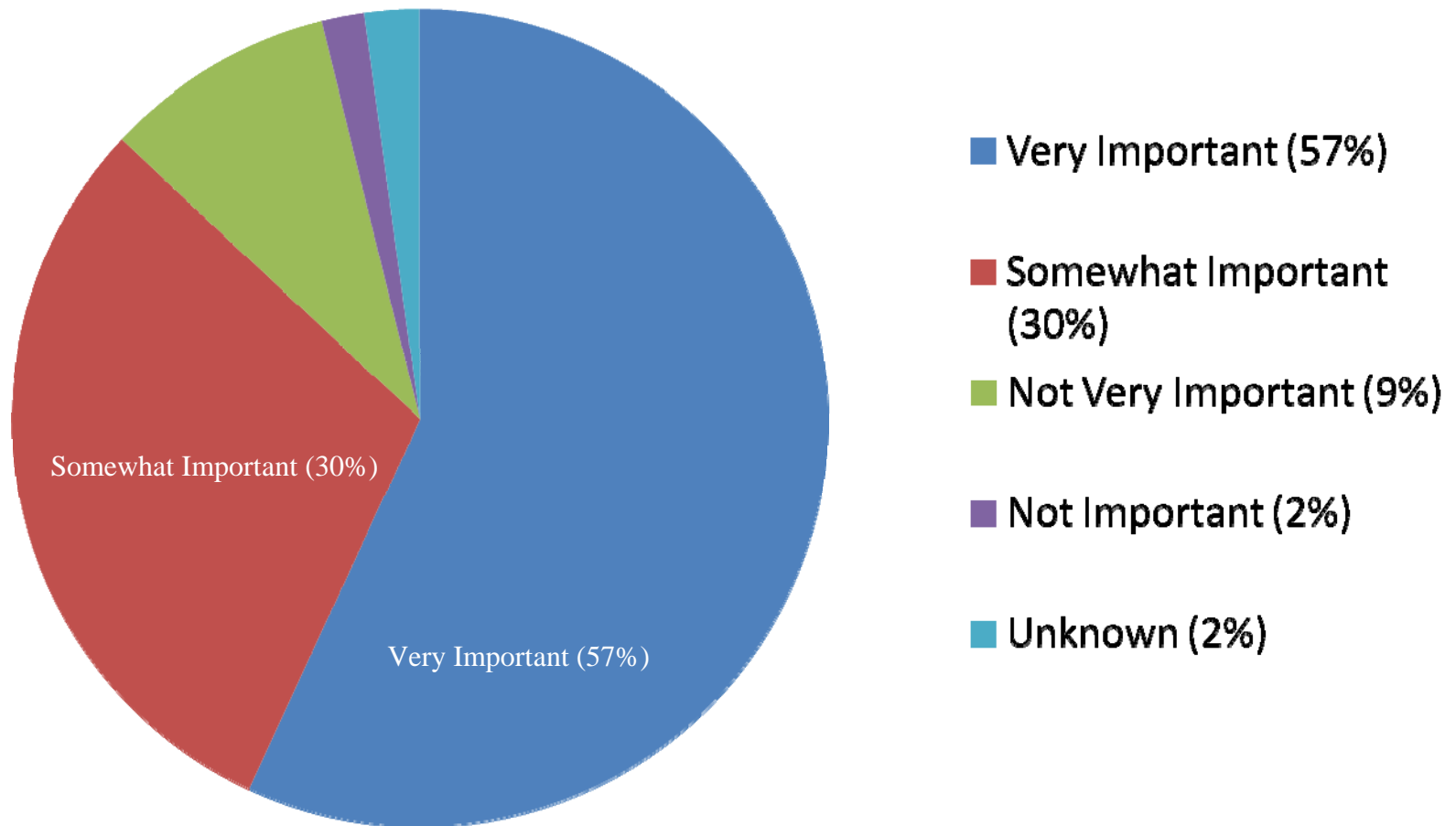
Very/Somewhat Important = 94%

Who is conducting the study (e.g., a medical school, a team of researchers, etc.)



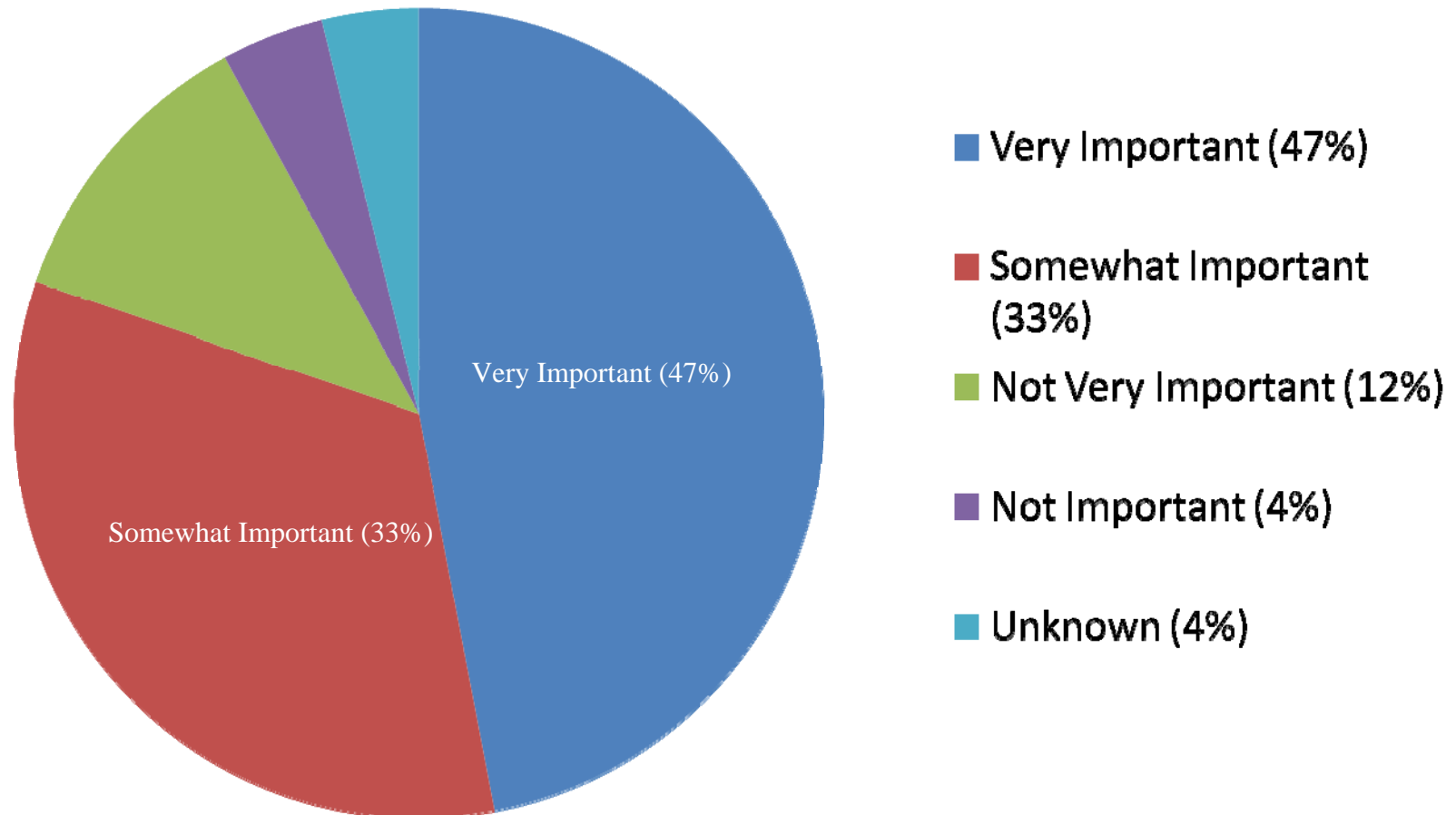
Very/Somewhat Important = 94%

# Who is paying for the study



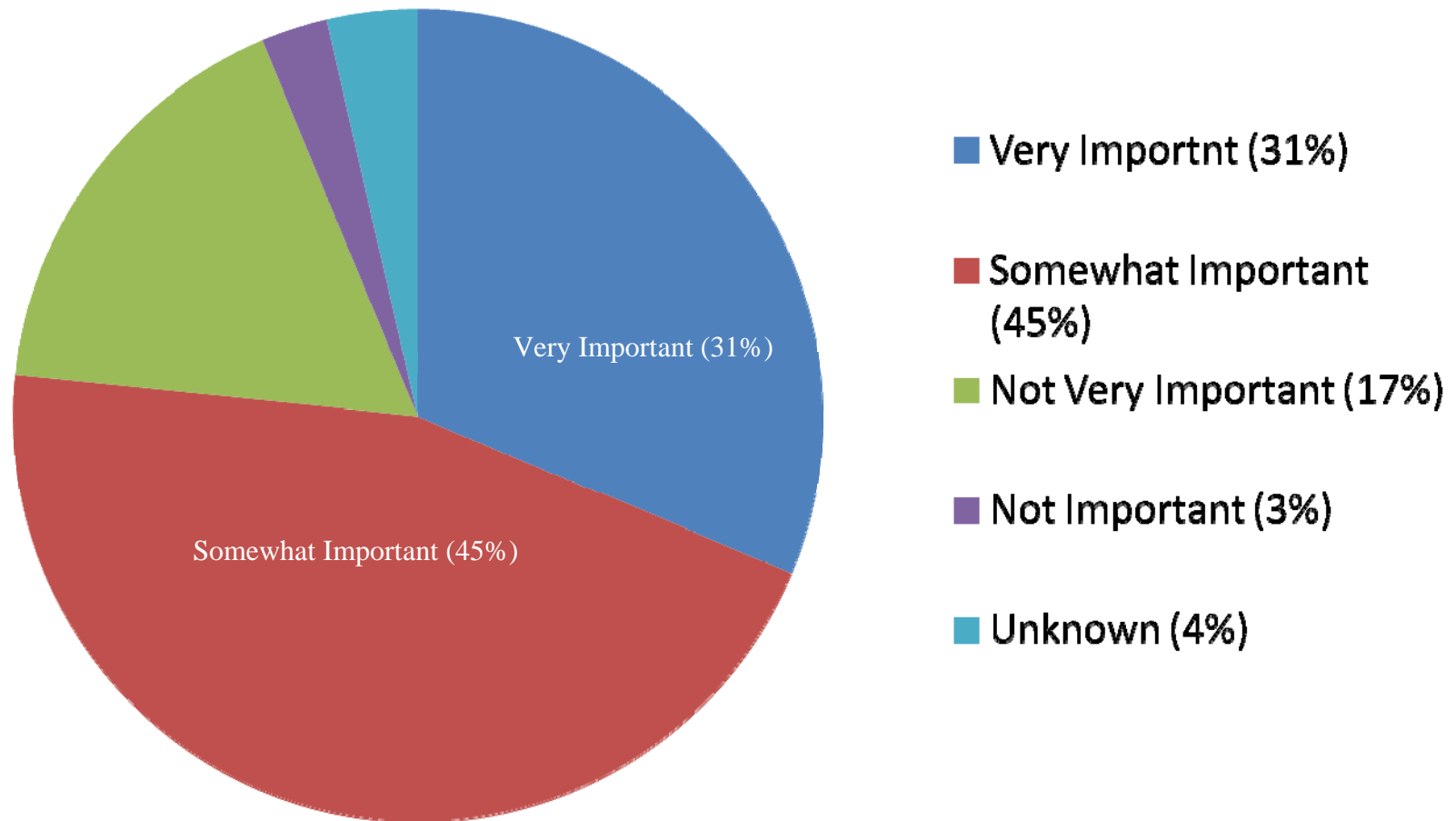
Very/Somewhat Important = 87%

# Whether mental health consumers are part of the research team



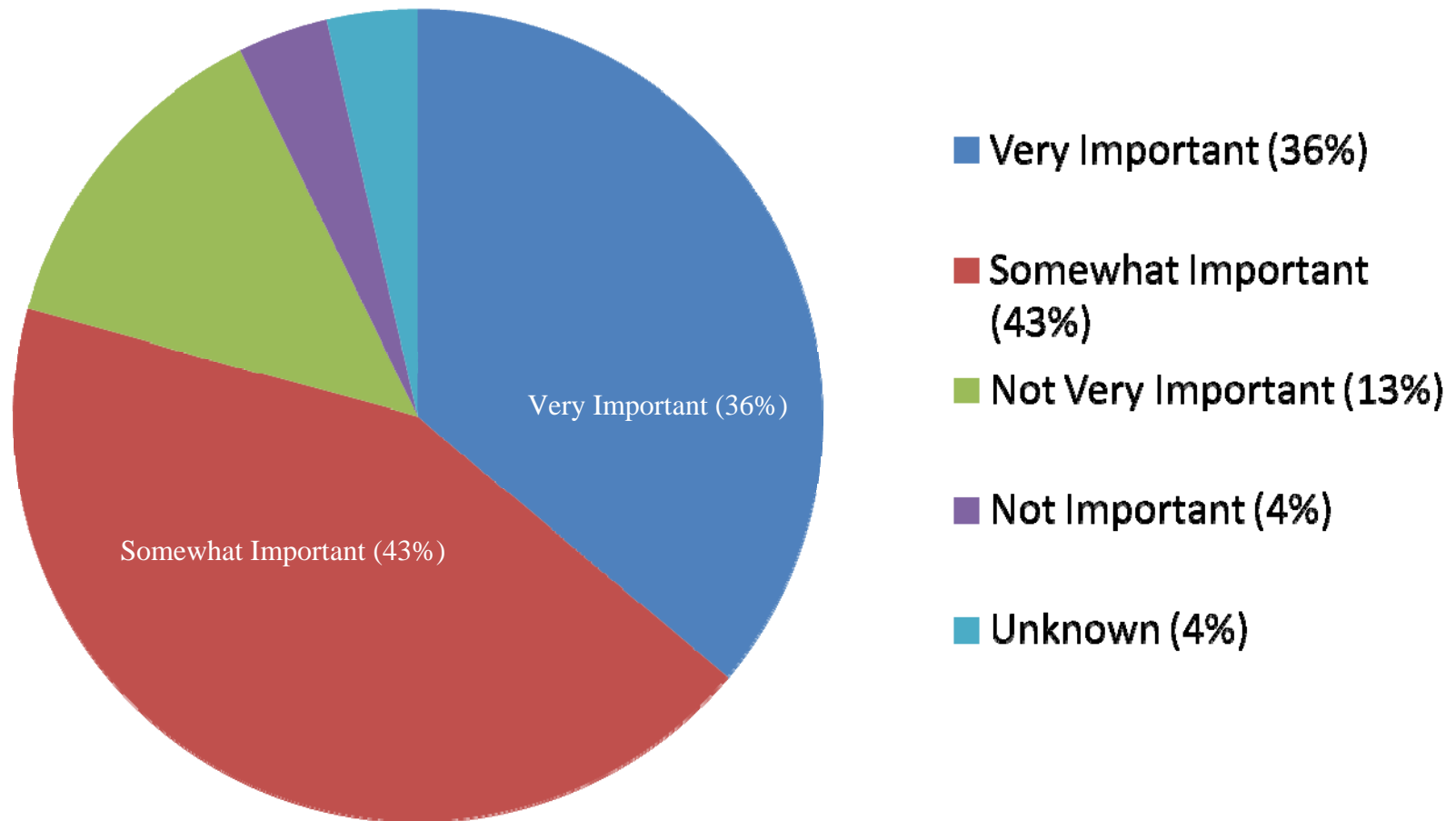
Very/Somewhat Important = 80%

# What other professionals who are not conducting the study say about it



Very/Somewhat Important = 76%

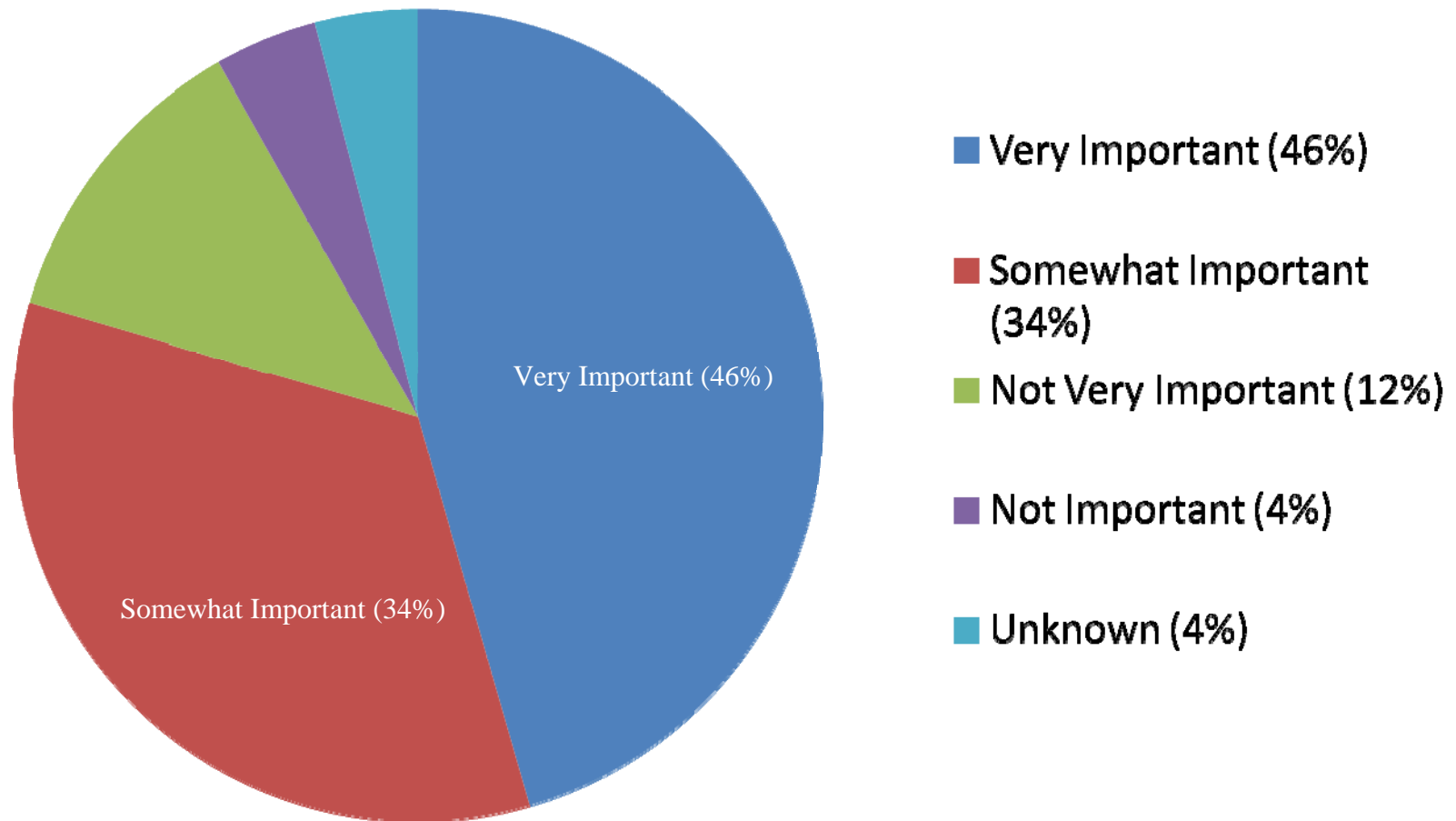
# What other mental health consumers say about the study



Very/Somewhat Important = 79%

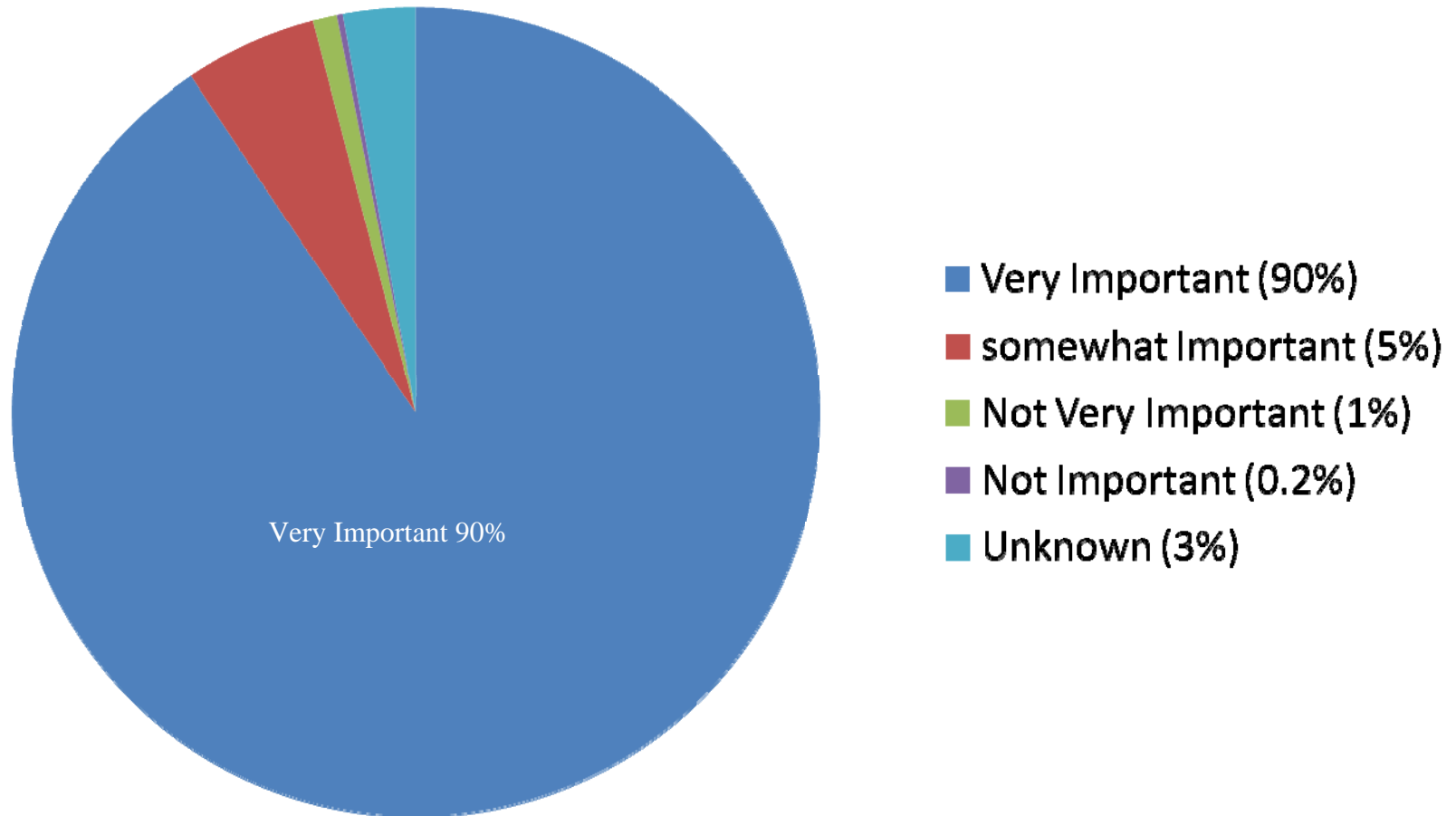


# A recommendation by a provider who's treating you



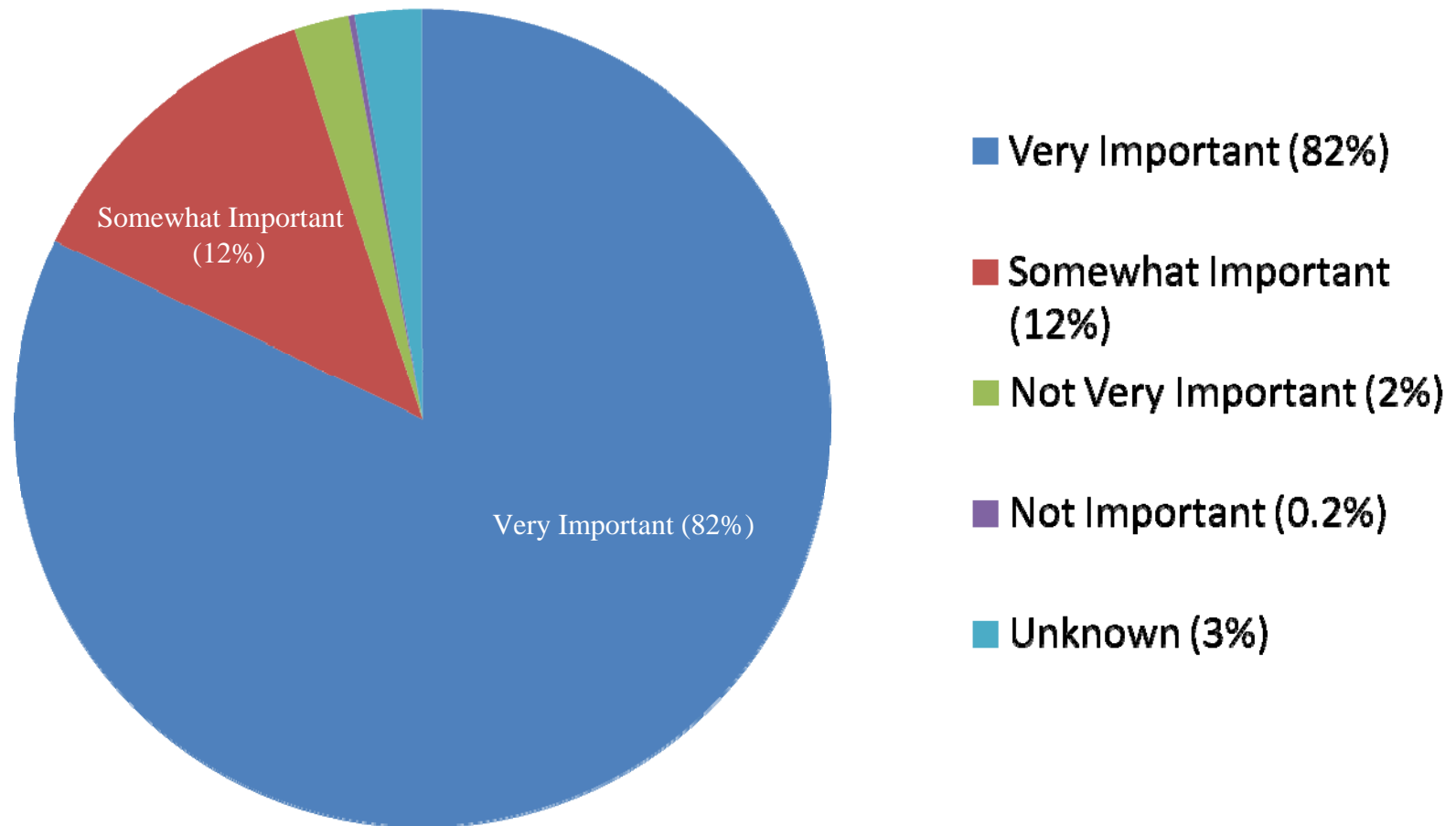
Very/Somewhat Important = 80%

# What the possible risks are



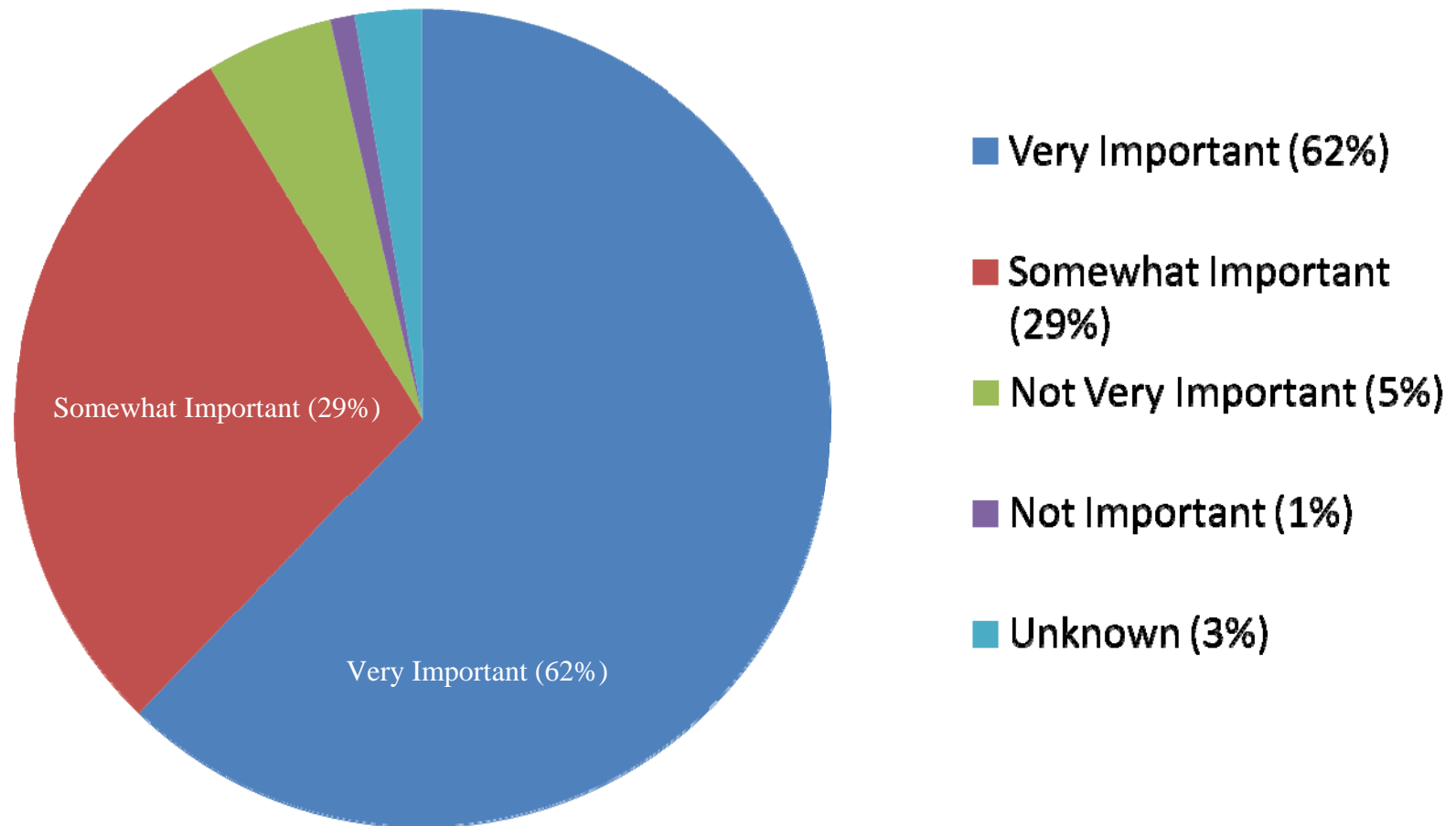
Very/Somewhat Important = 95%

# Your right to withdraw from the research study



Very/Somewhat Important = 94%

# Whether the study's results will be sent to you

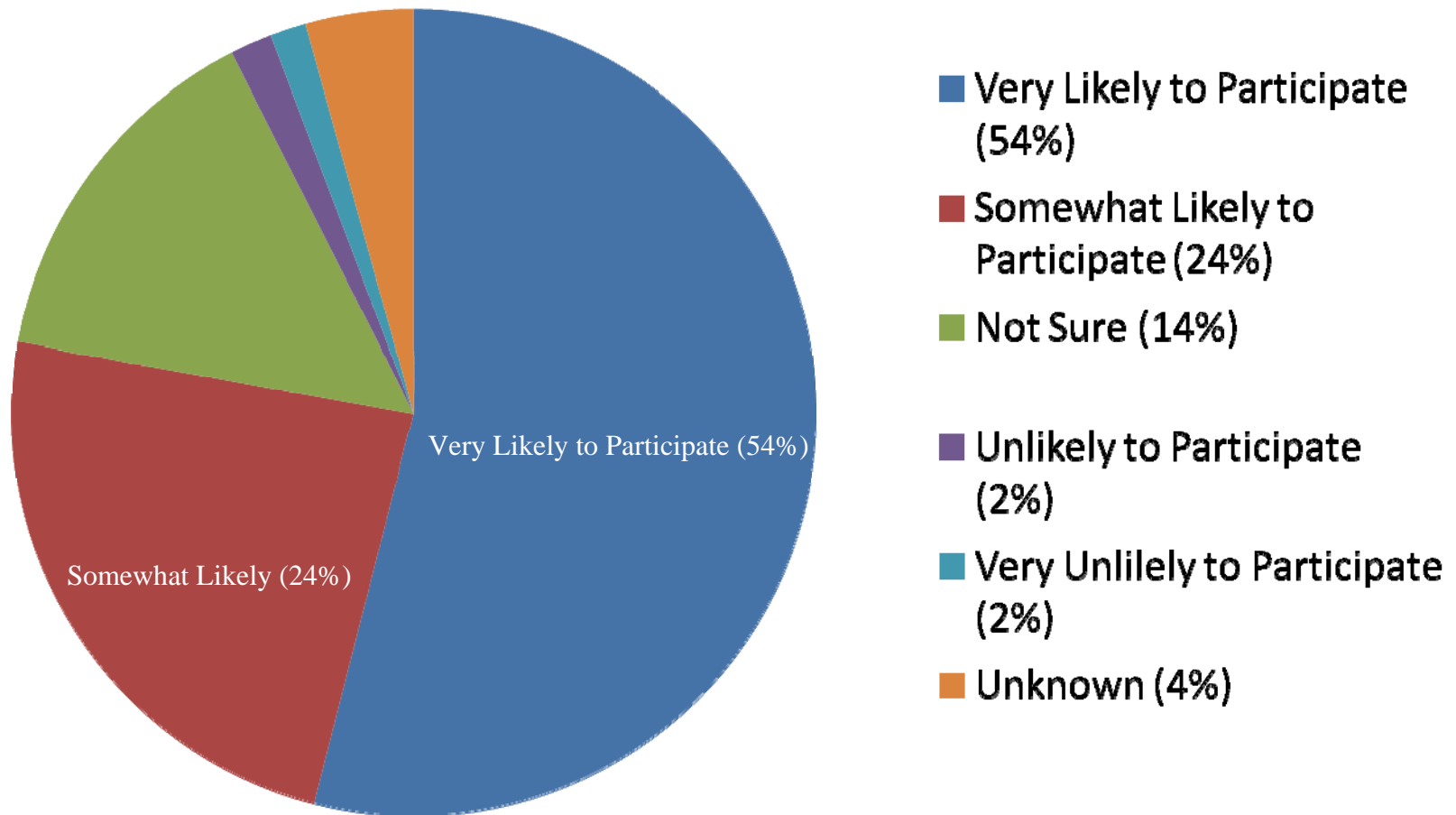


Very/Somewhat Important = 91%

## Part 3: Participation

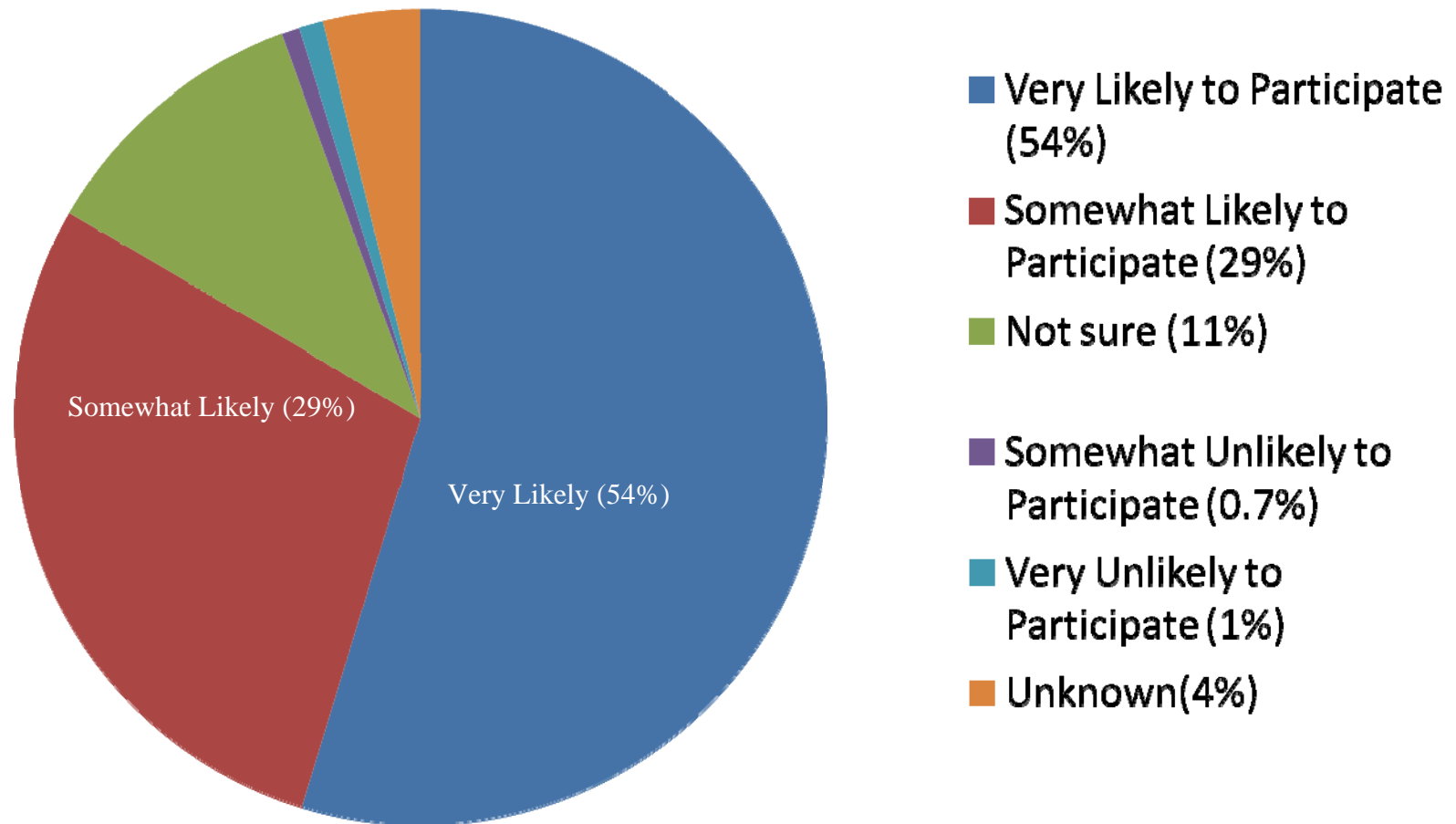
- Would you be more or less likely to participate in a study that:

# Was run by your clinician/provider



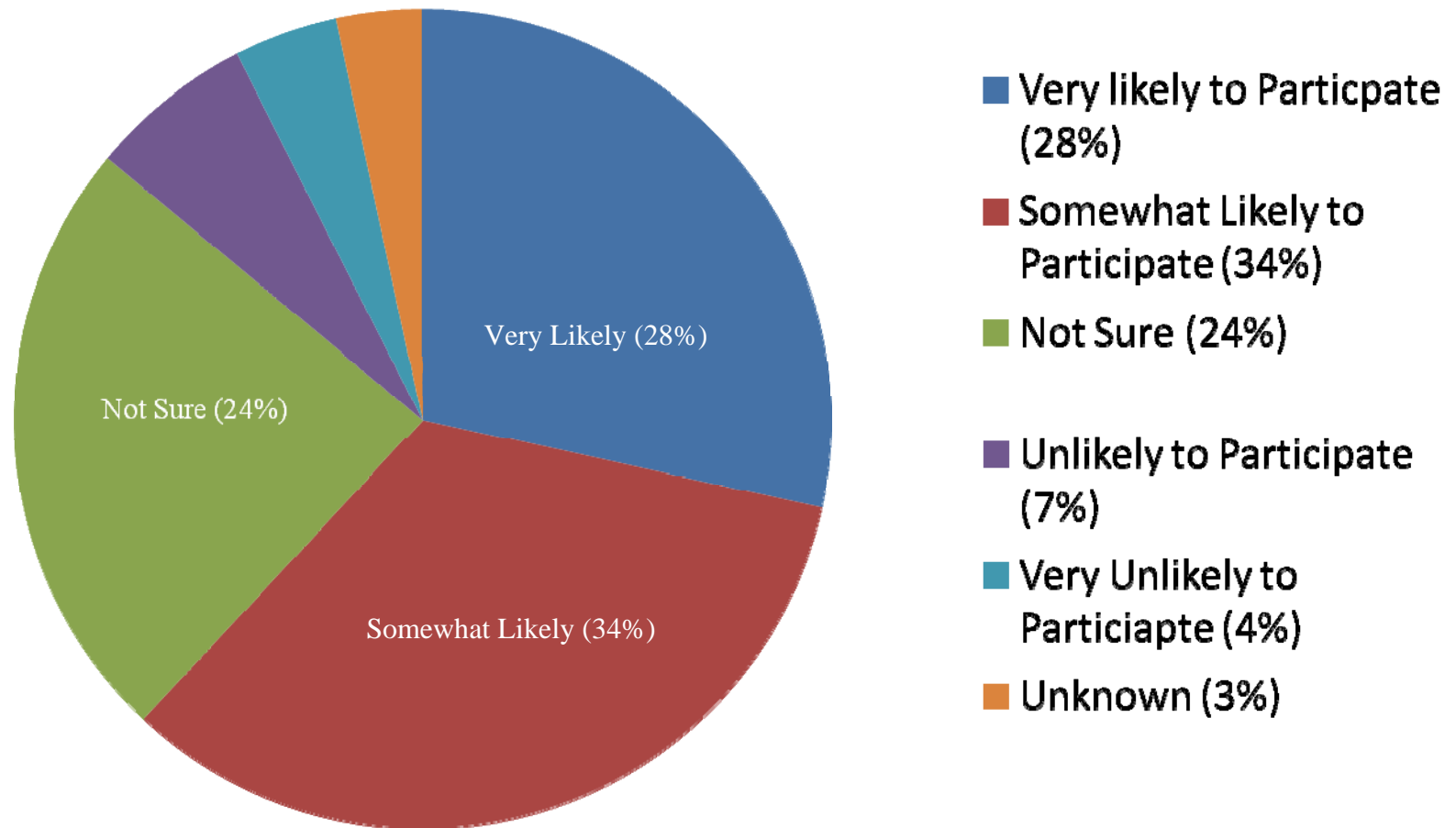
Very/Somewhat Likely to Participate = 78%

# Was endorsed by your clinician/provider



Very/Somewhat Likely to Participate = 83%

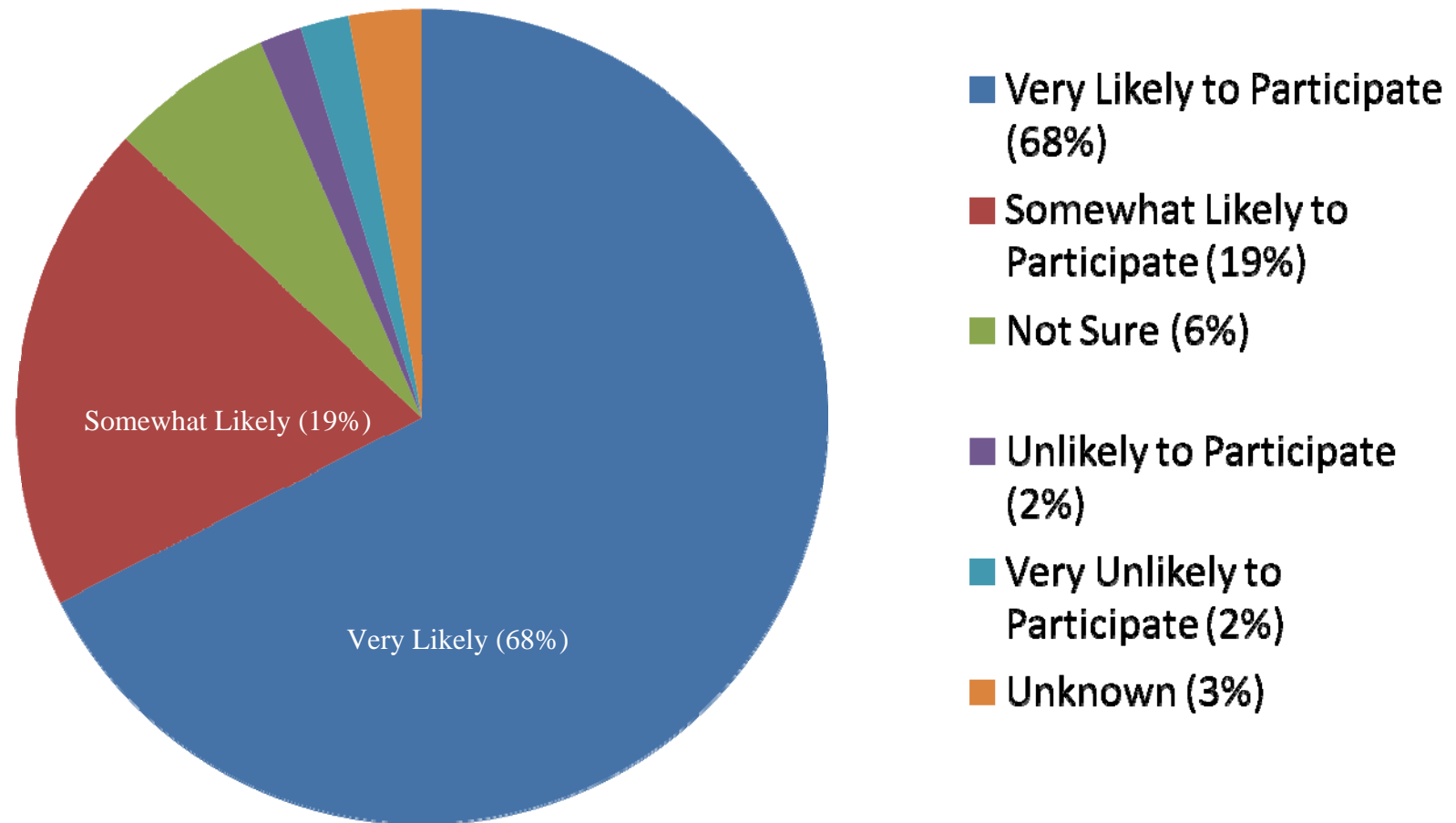
# Was testing a new medication(s) for your condition



Very/Somewhat Likely to Participate = 62%

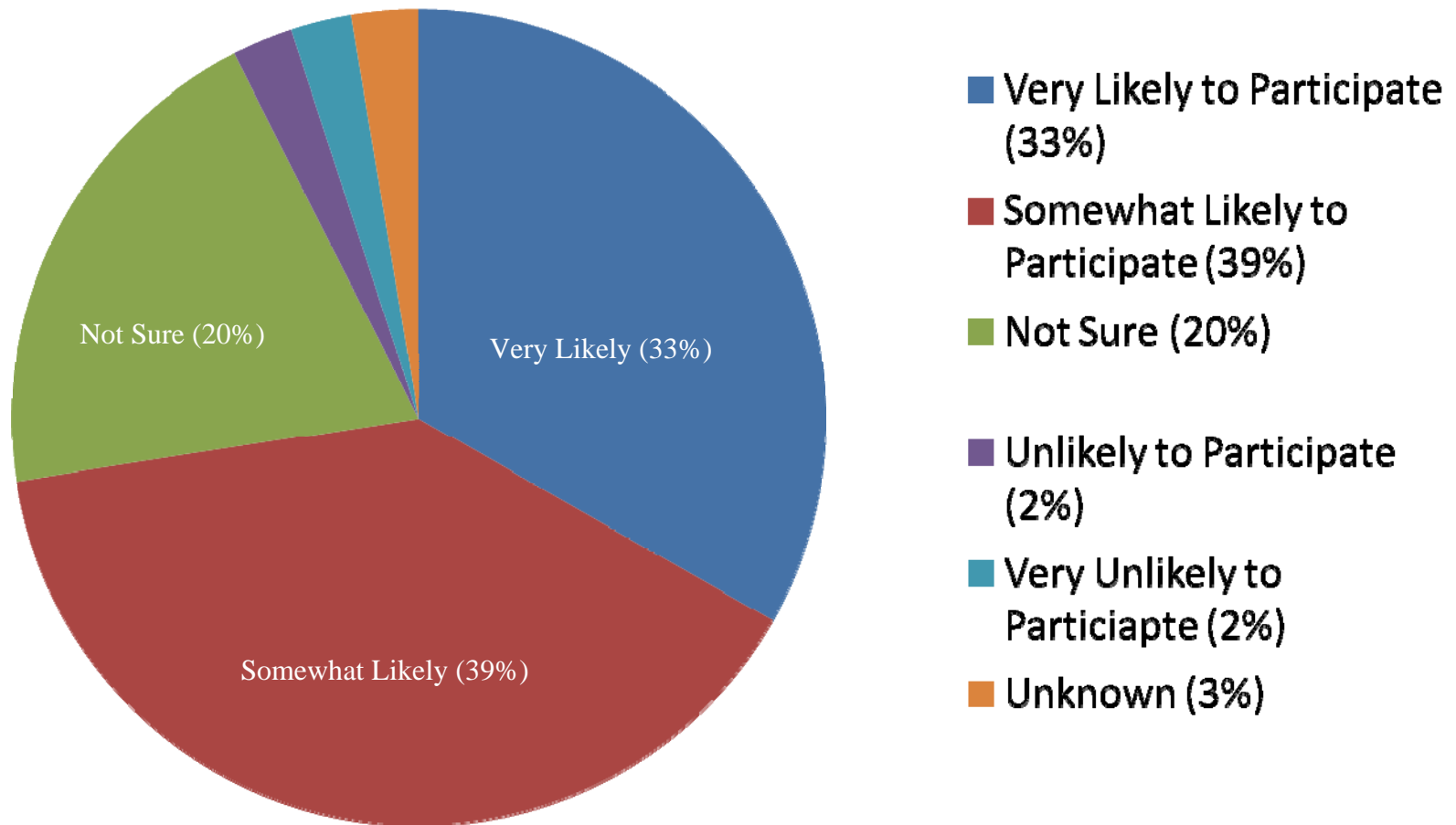


# Was testing a new talk therapy for your condition



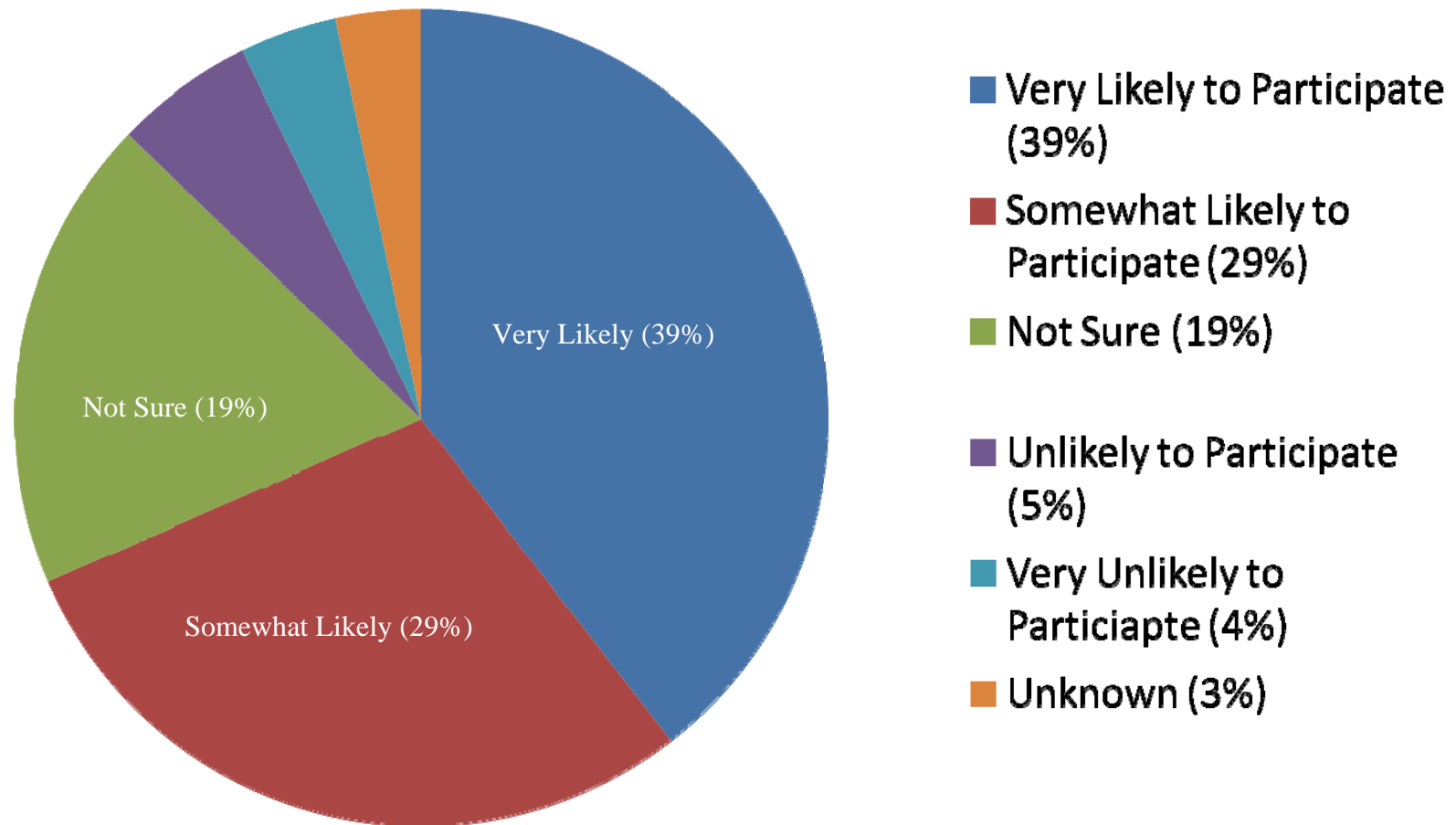
Very/Somewhat Likely to Participate = 87%

# Required you to Participate in Medical Tests



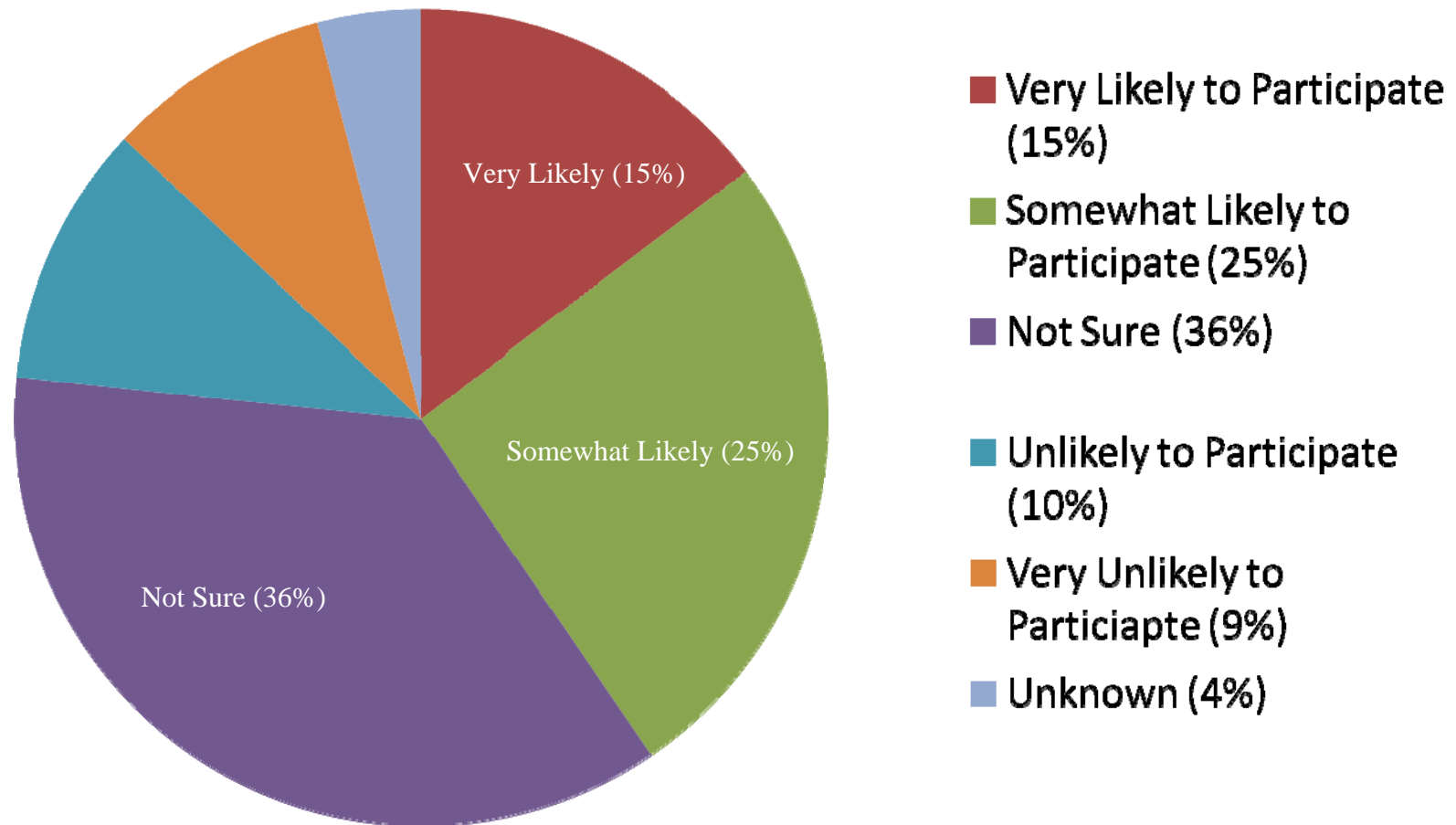
Very/Somewhat Likely to Participate = 72%

# Make information from your medical records available for research on your conditions



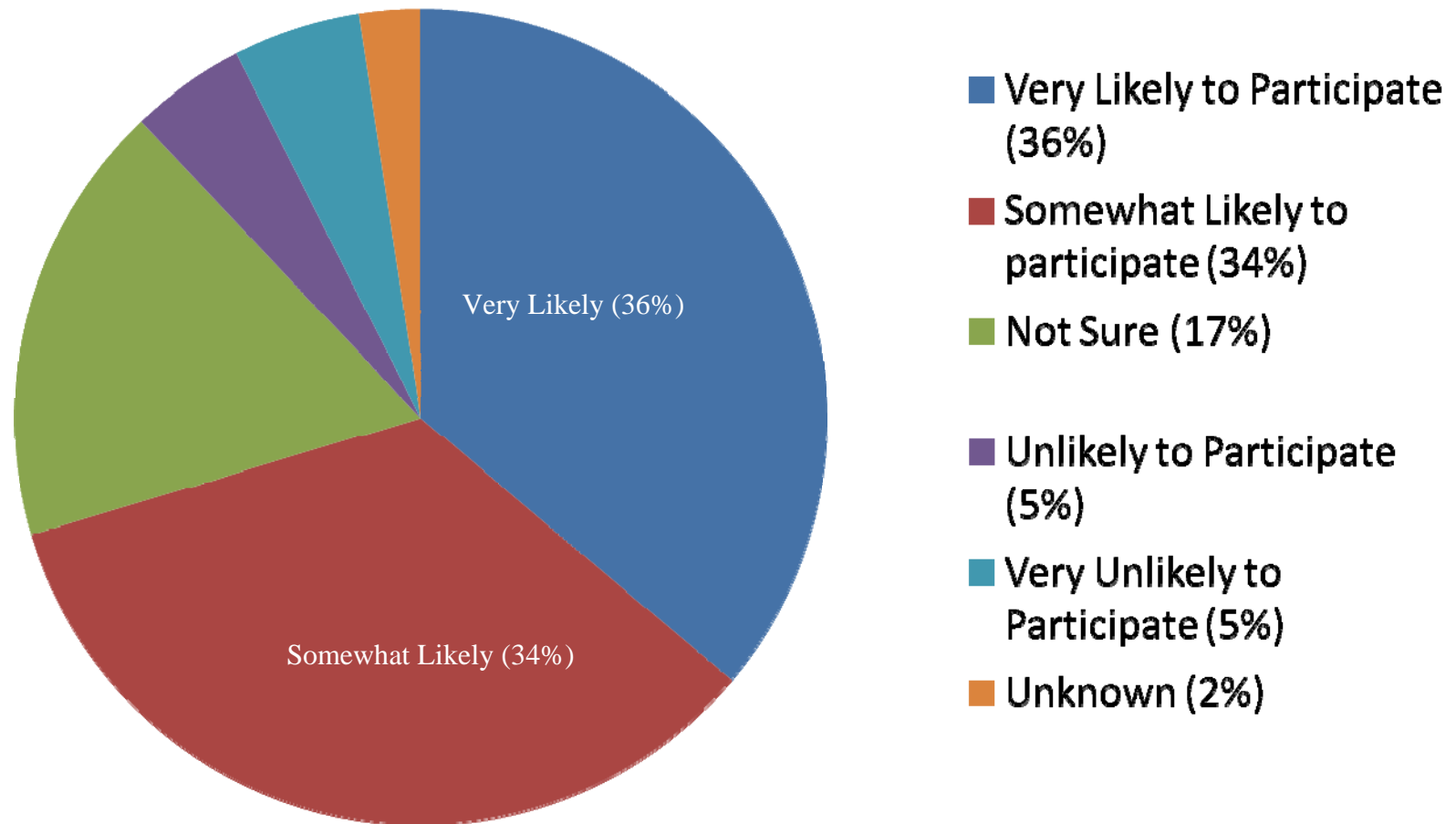
Very/Somewhat Likely to Participate = 68%

# Required you to change your current course of treatment



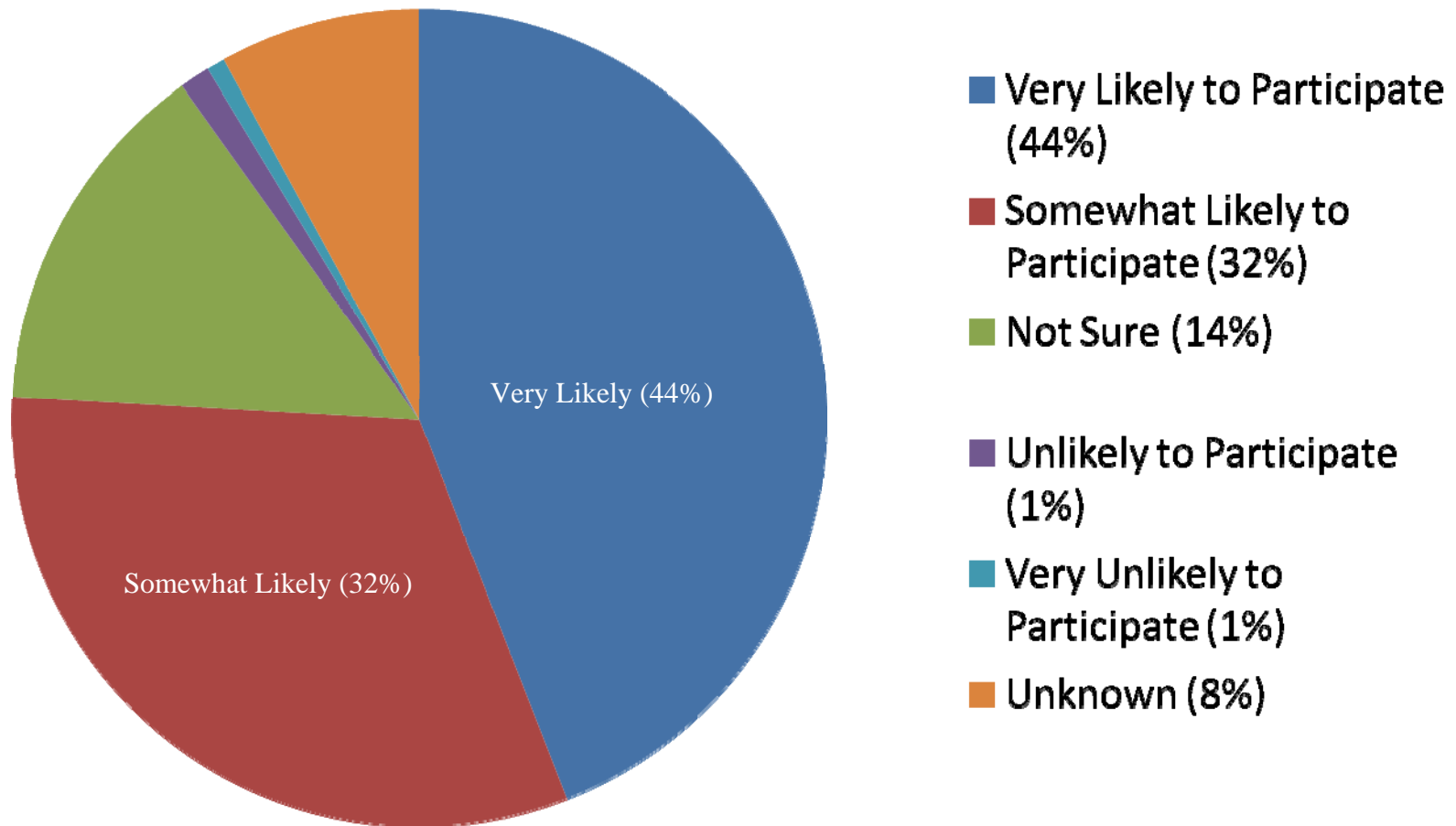
Very/Somewhat Likely to Participate = 40%

# Required you to provide tissue or gene samples for long-term comparison and analysis of treatment responses



Very/Somewhat Likely to Participate = 70%

# Offered some form of compensation (monetary gift card)

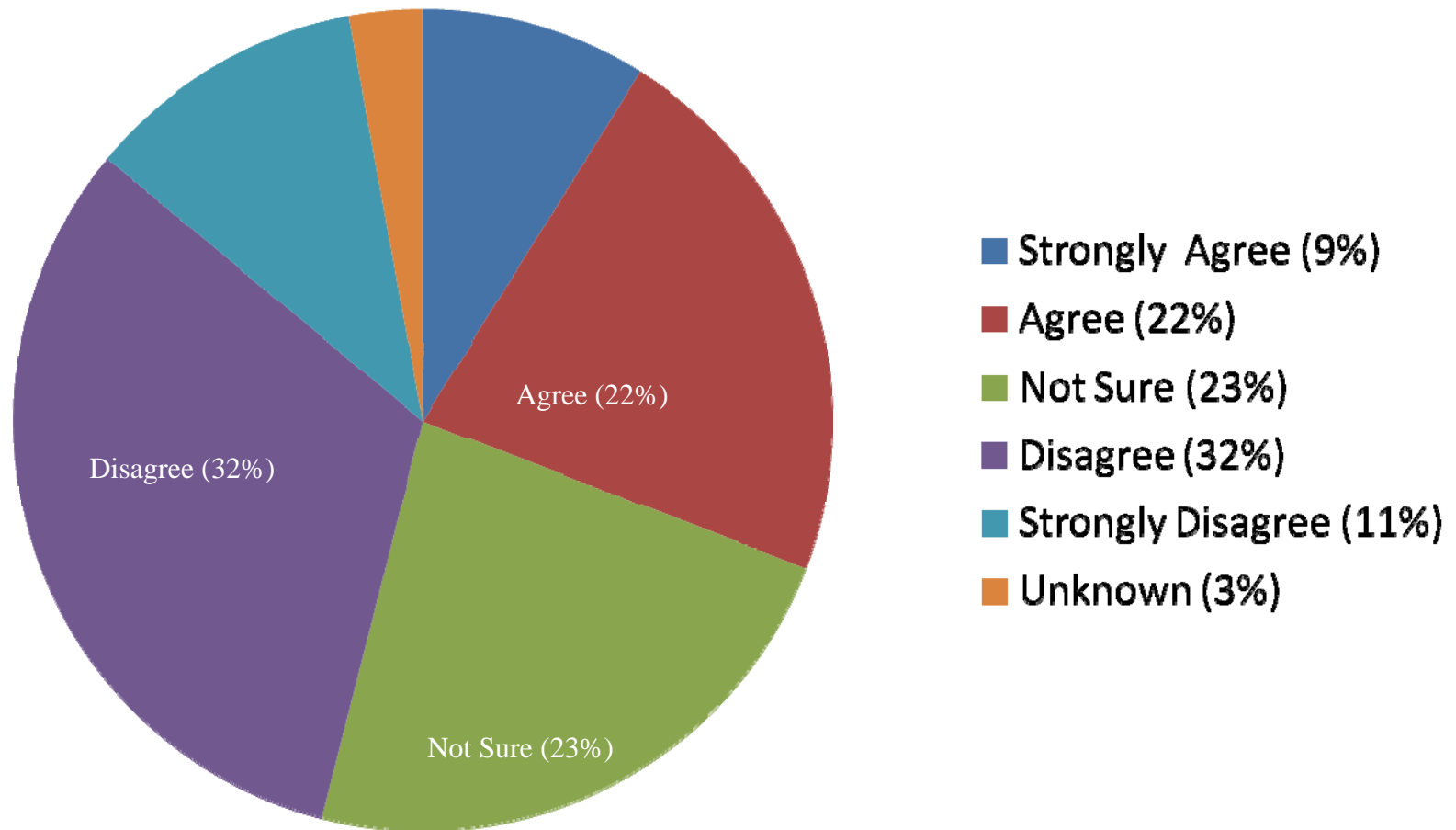


Very/Somewhat Likely to Participate = 76%

- Part 4: Reasons to Not Participate

Below are some reasons why people choose not to participate in research studies. Please state how these concerns would influence your decision to participate in a study.

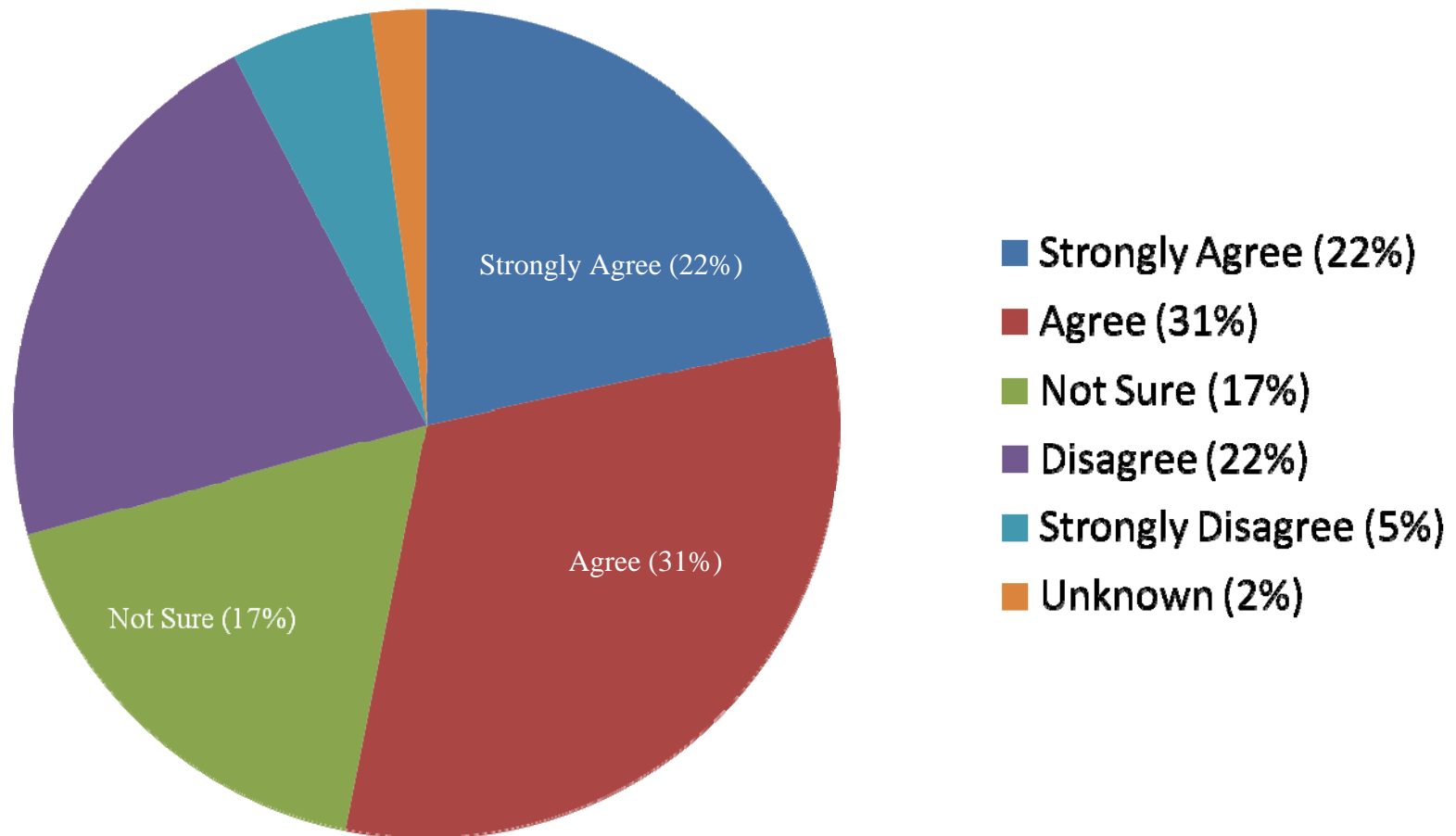
# It would be too inconvenient, and I don't have time



Strongly Agree/Agree = 31%

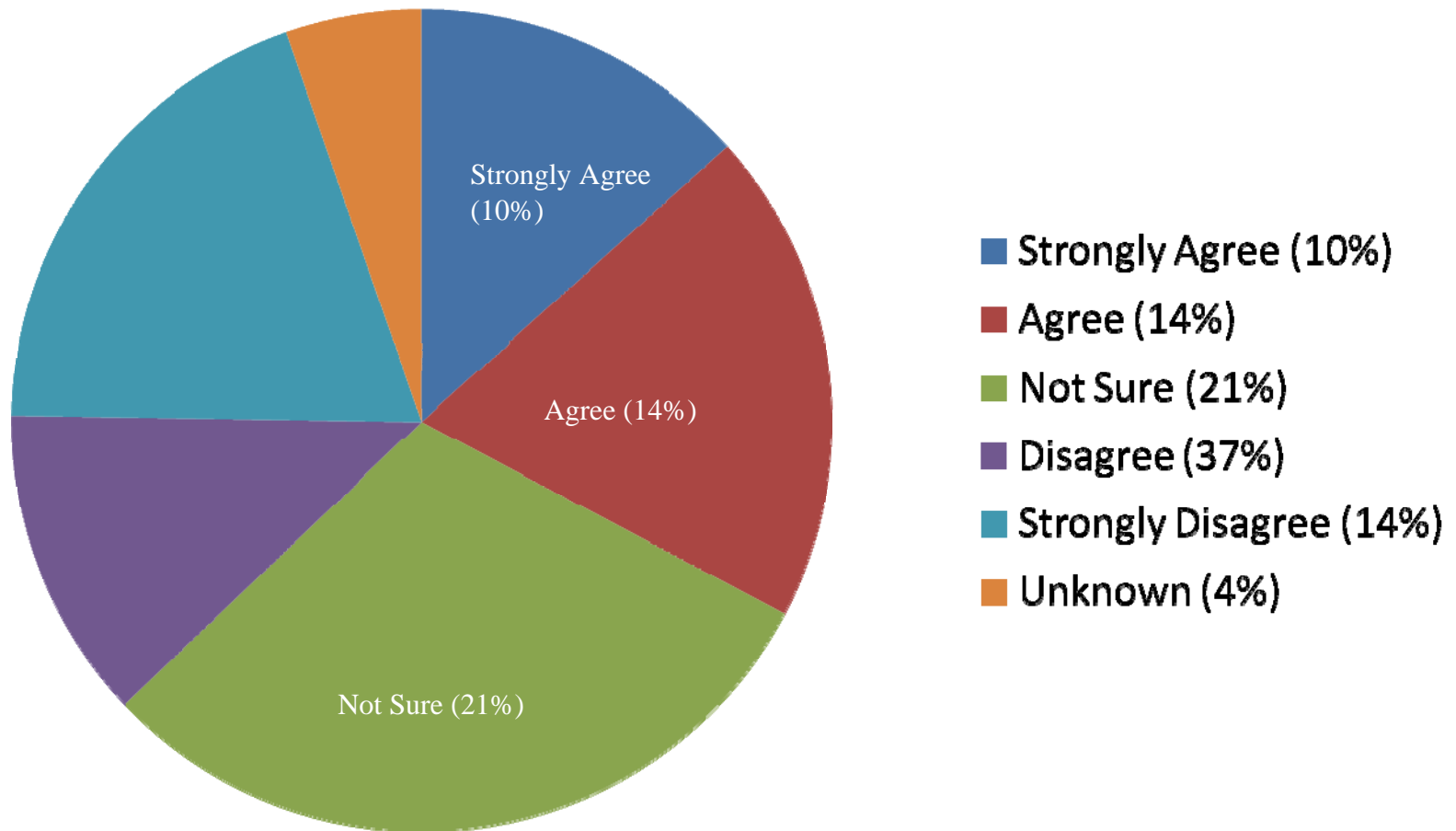


I have concerns about whether the researchers would be honest about the risks and procedures



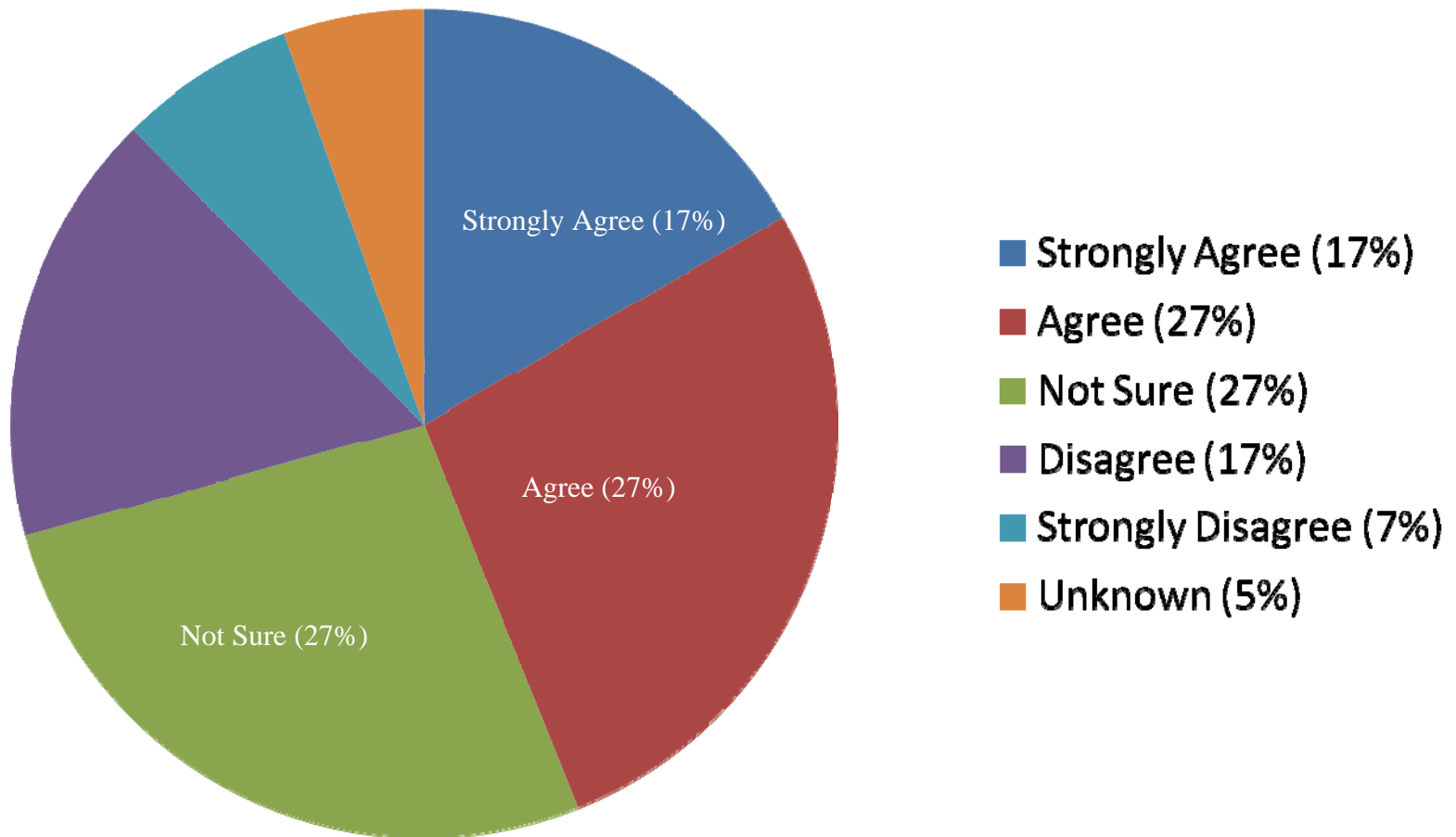
Strongly Agree/Agree = 53%

# I don't want to be “experimented” on



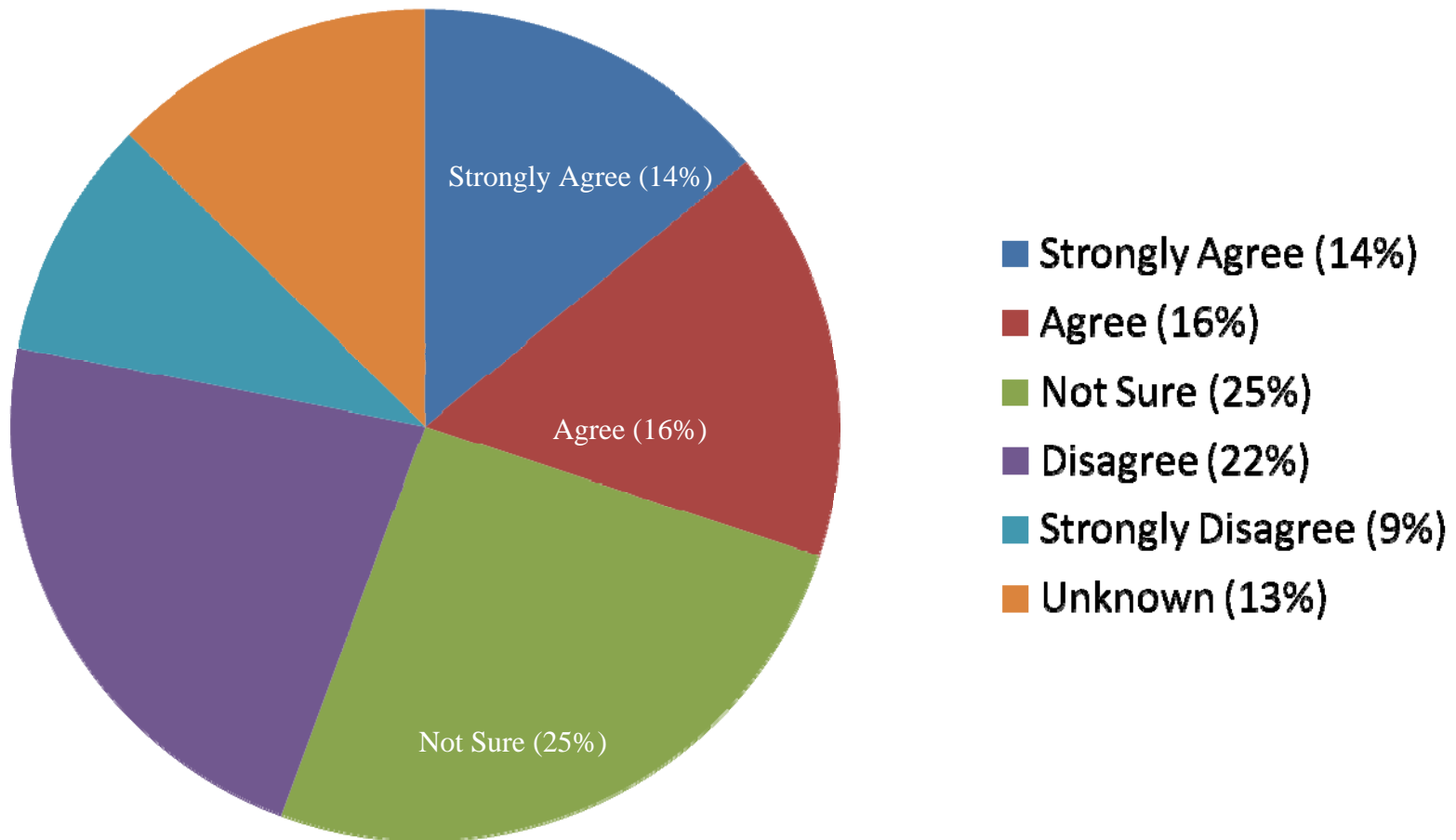
Strongly Agree/Agree = 24%

# I am afraid I'll have to change medicines or treatment



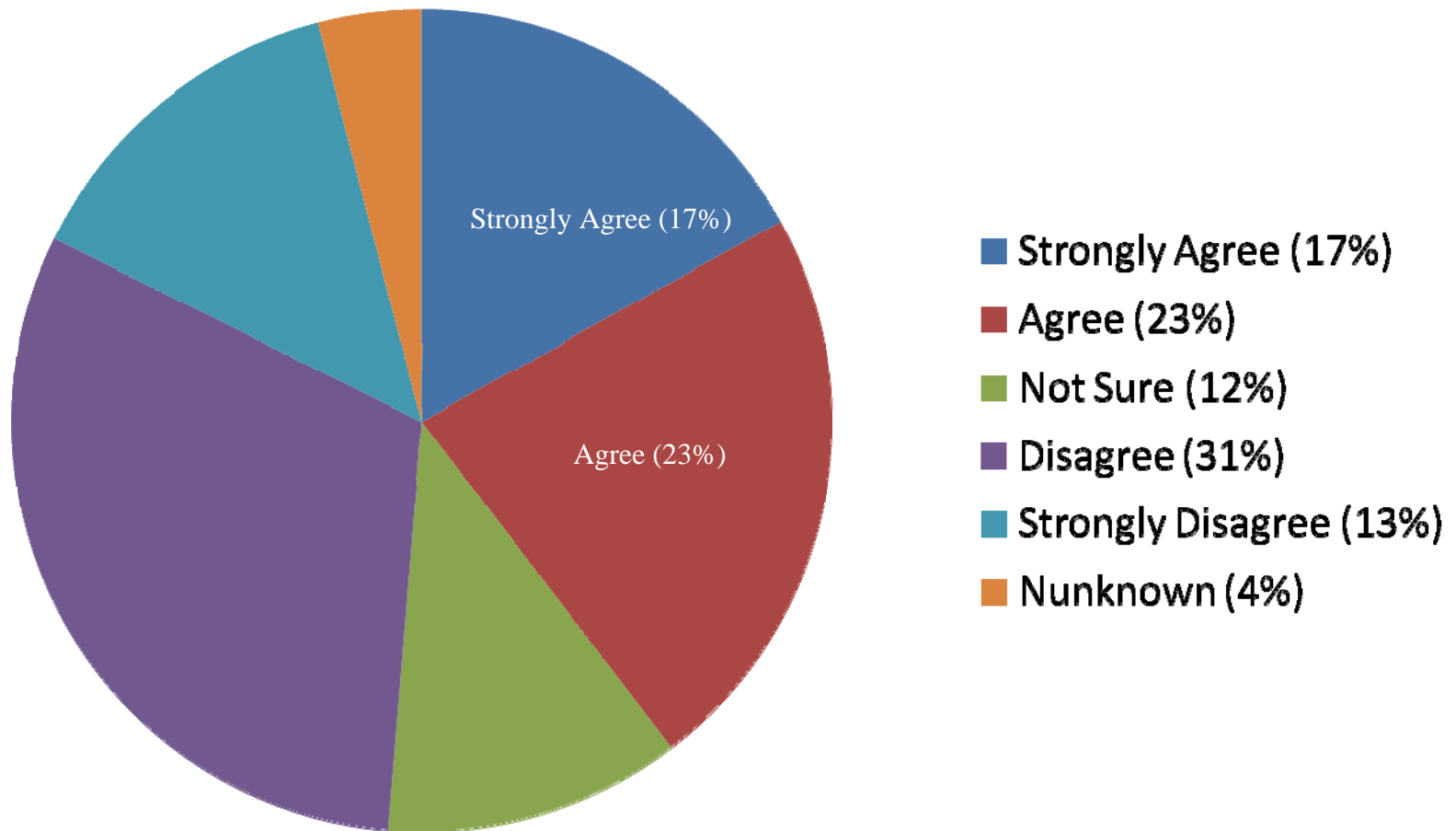
Strongly Agree/Agree = 44%

# I am worried that it might affect my insurance coverage



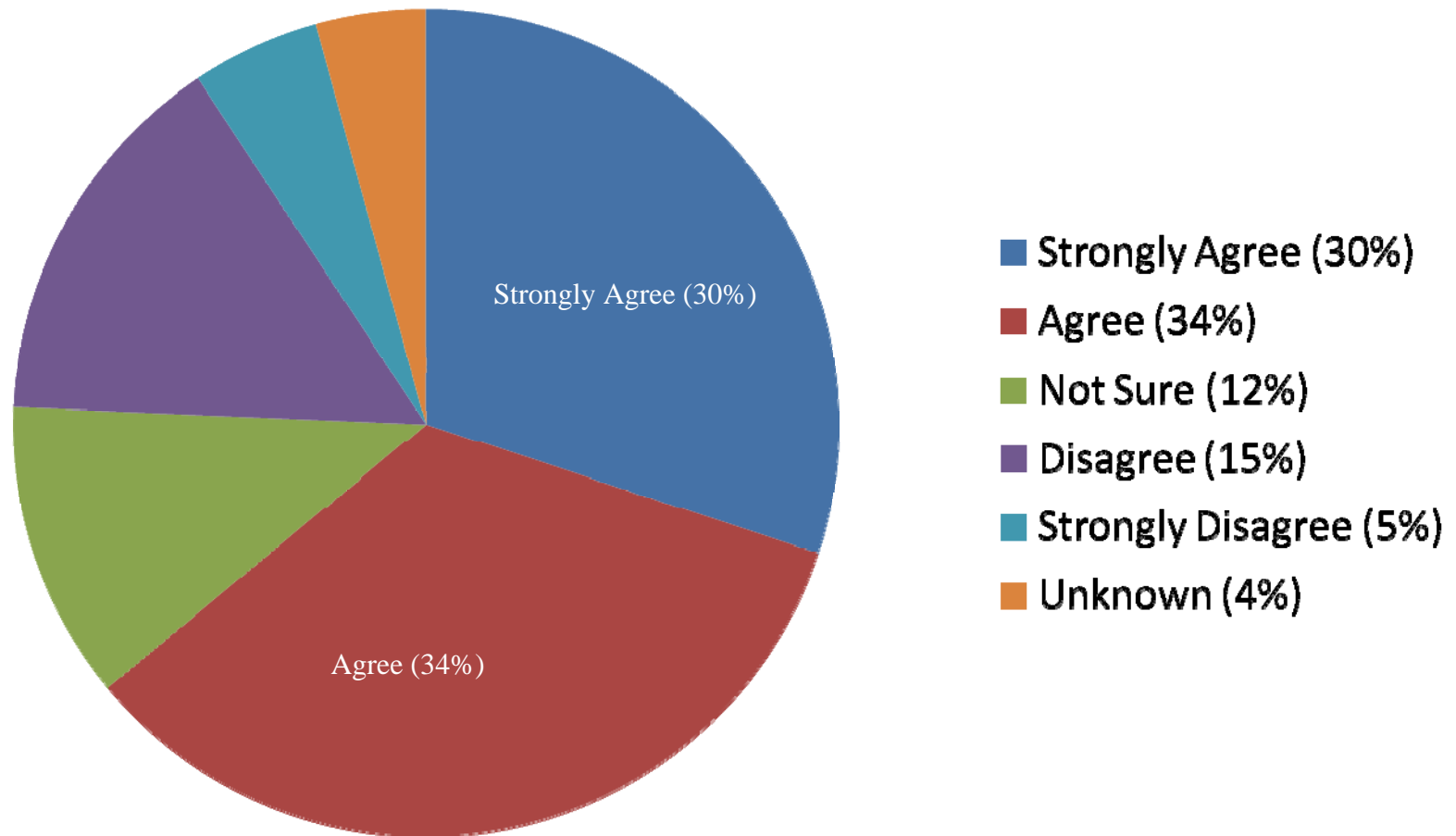
Strongly Agree/Agree = 30%

# I am worried about Confidentiality



Strongly Agree/Agree = 40%

I don't know where to find information  
about research studies that I could  
participate in

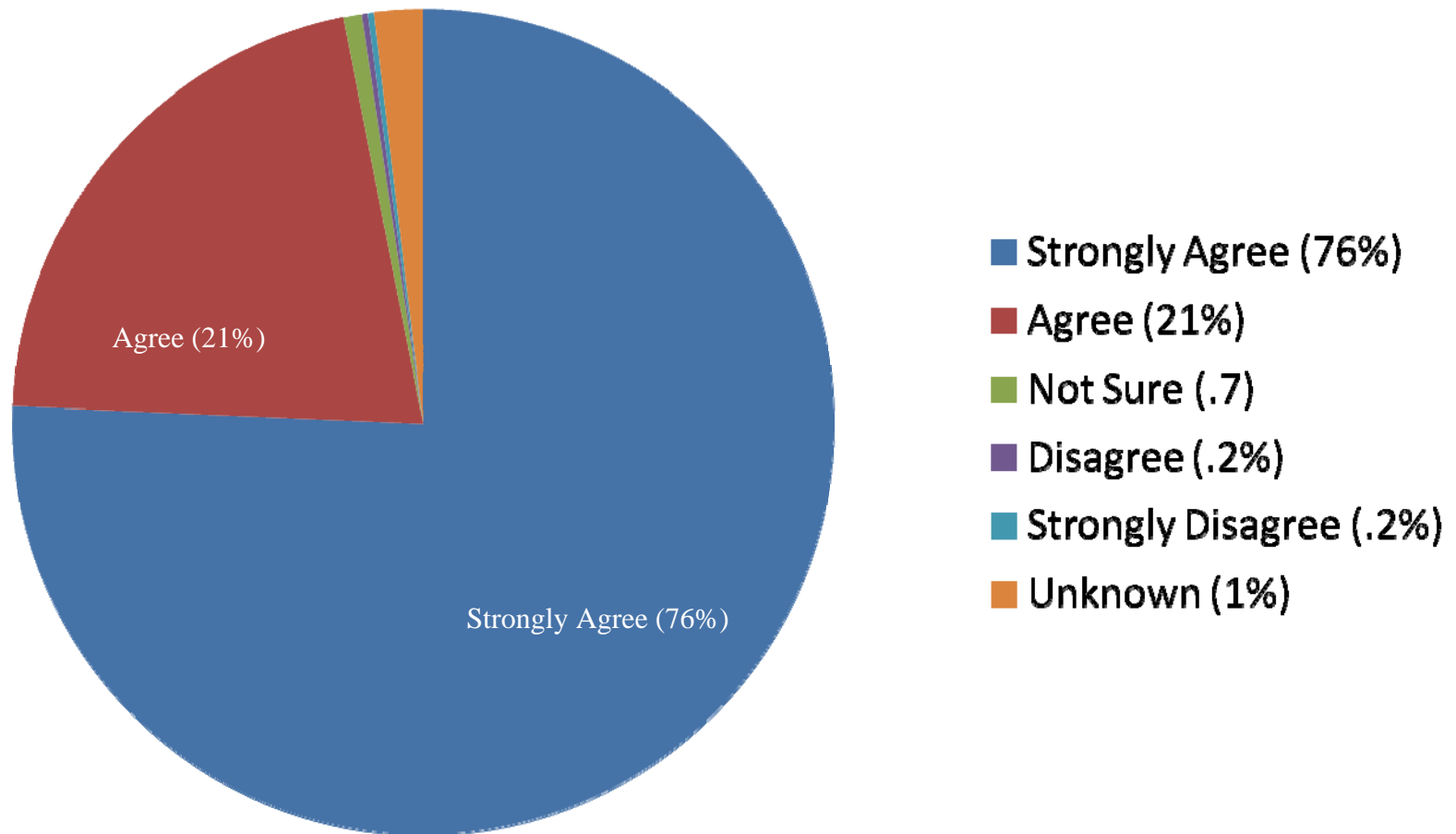


Strongly Agree/Agree = 64%

## Part 5 – Reasons to Participate

- Below are some reasons why people choose to participate in research studies. Please indicate how these reasons would influence your decision to participate in a study.

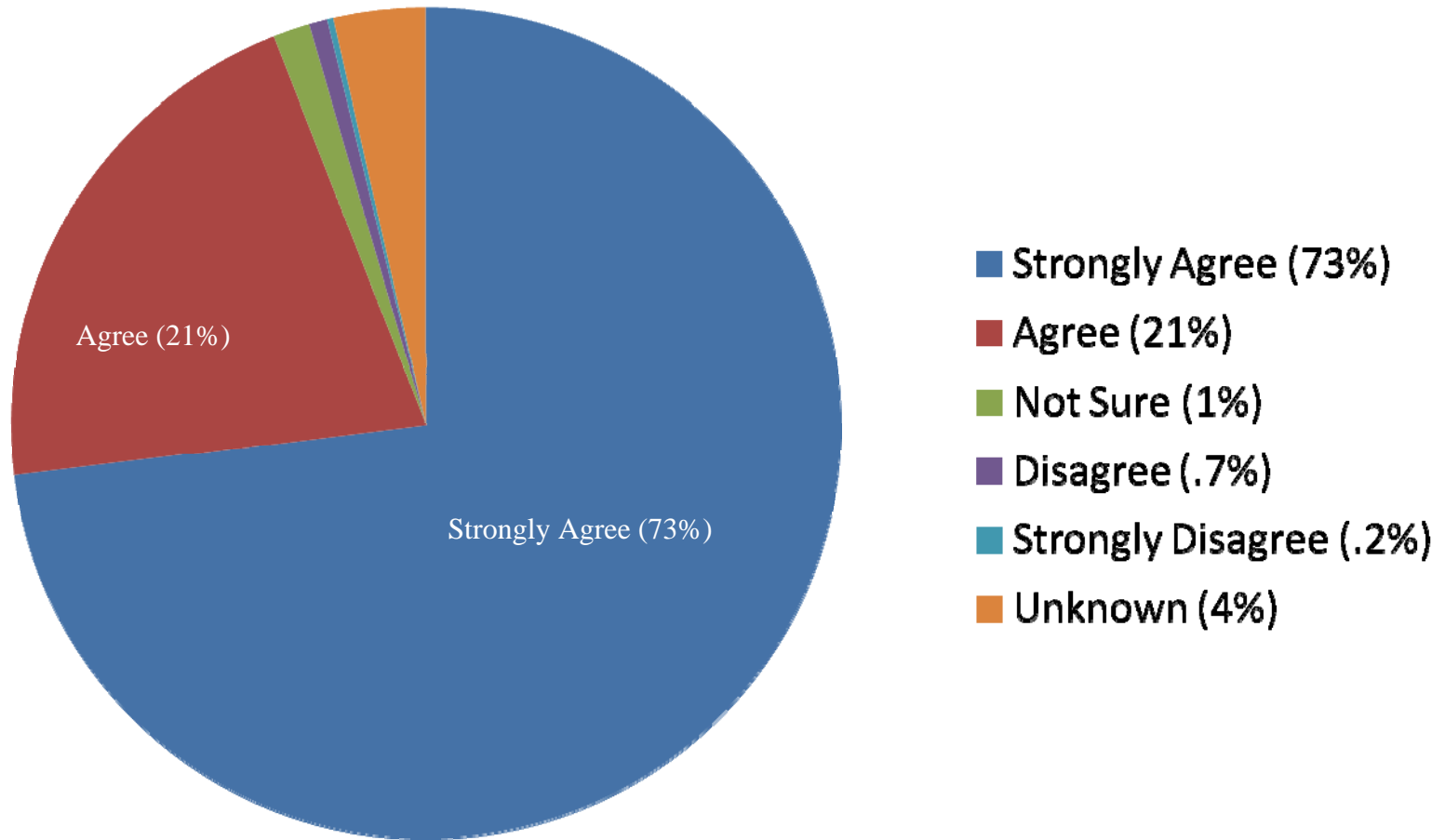
# I would like to help others or myself in the long run



Strongly Agree/Agree = 97%

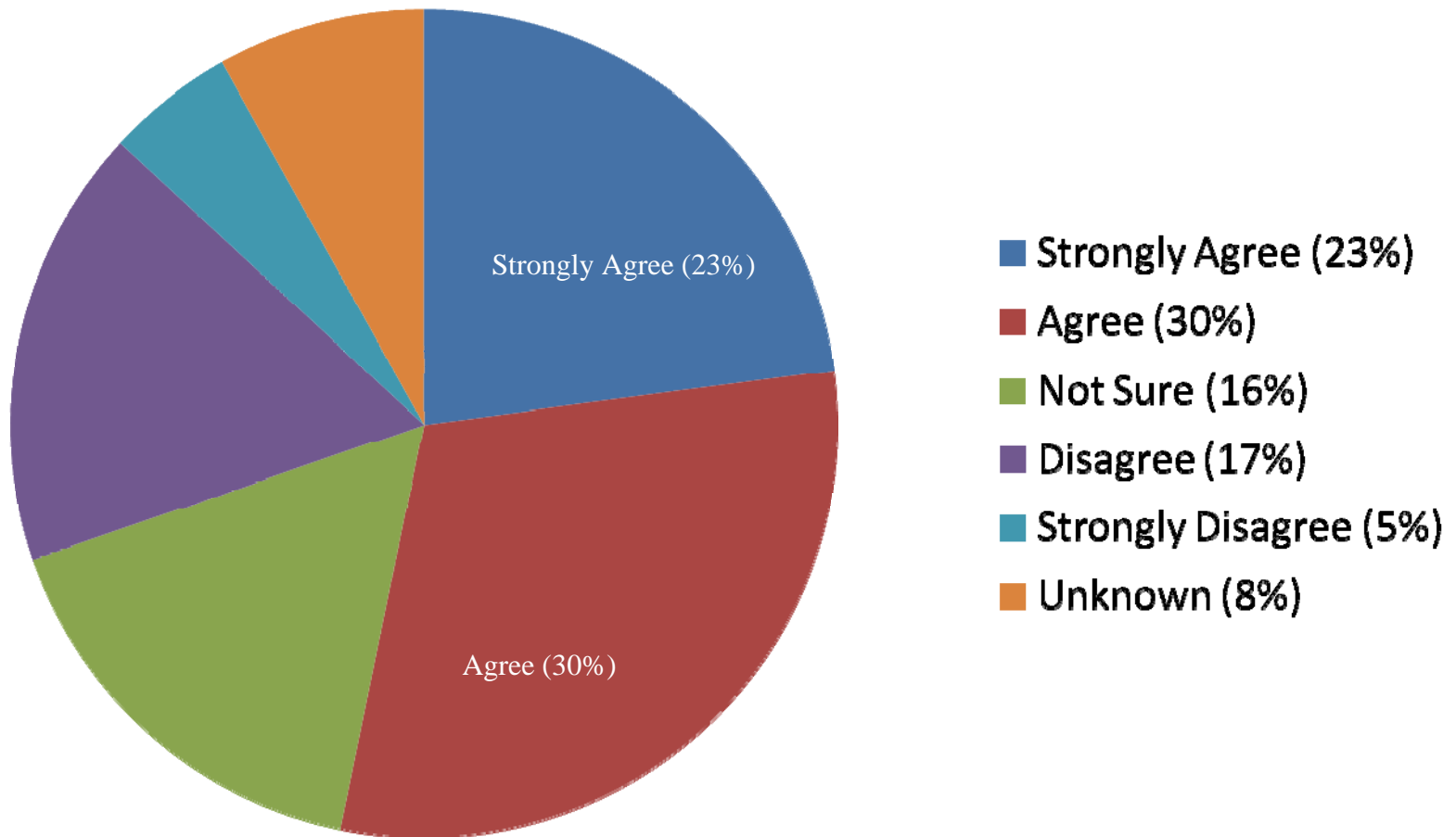


# I would like to improve the quality of my care



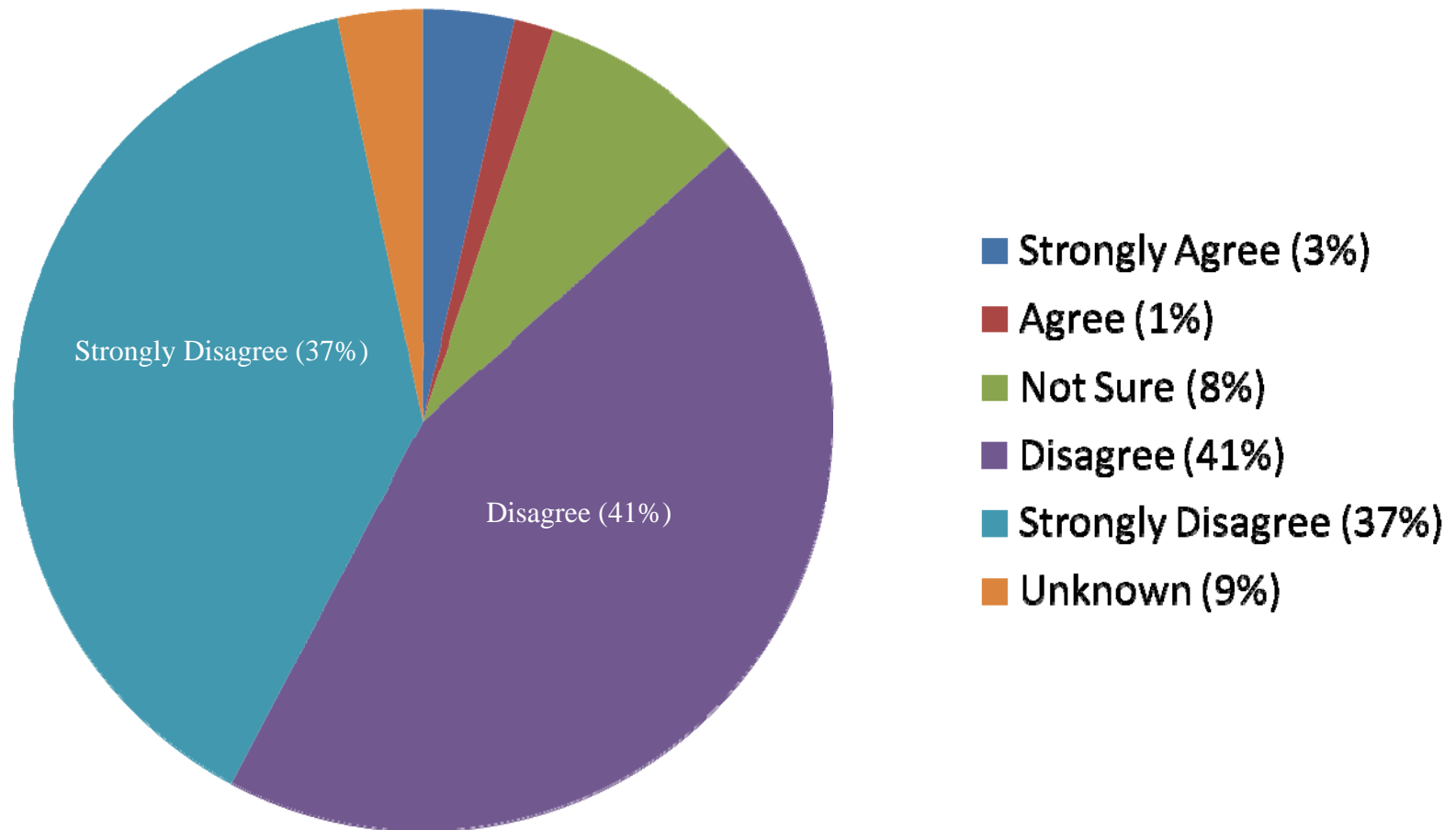
Strongly Agree/Agree = 94%

# I would like to earn money or other rewards



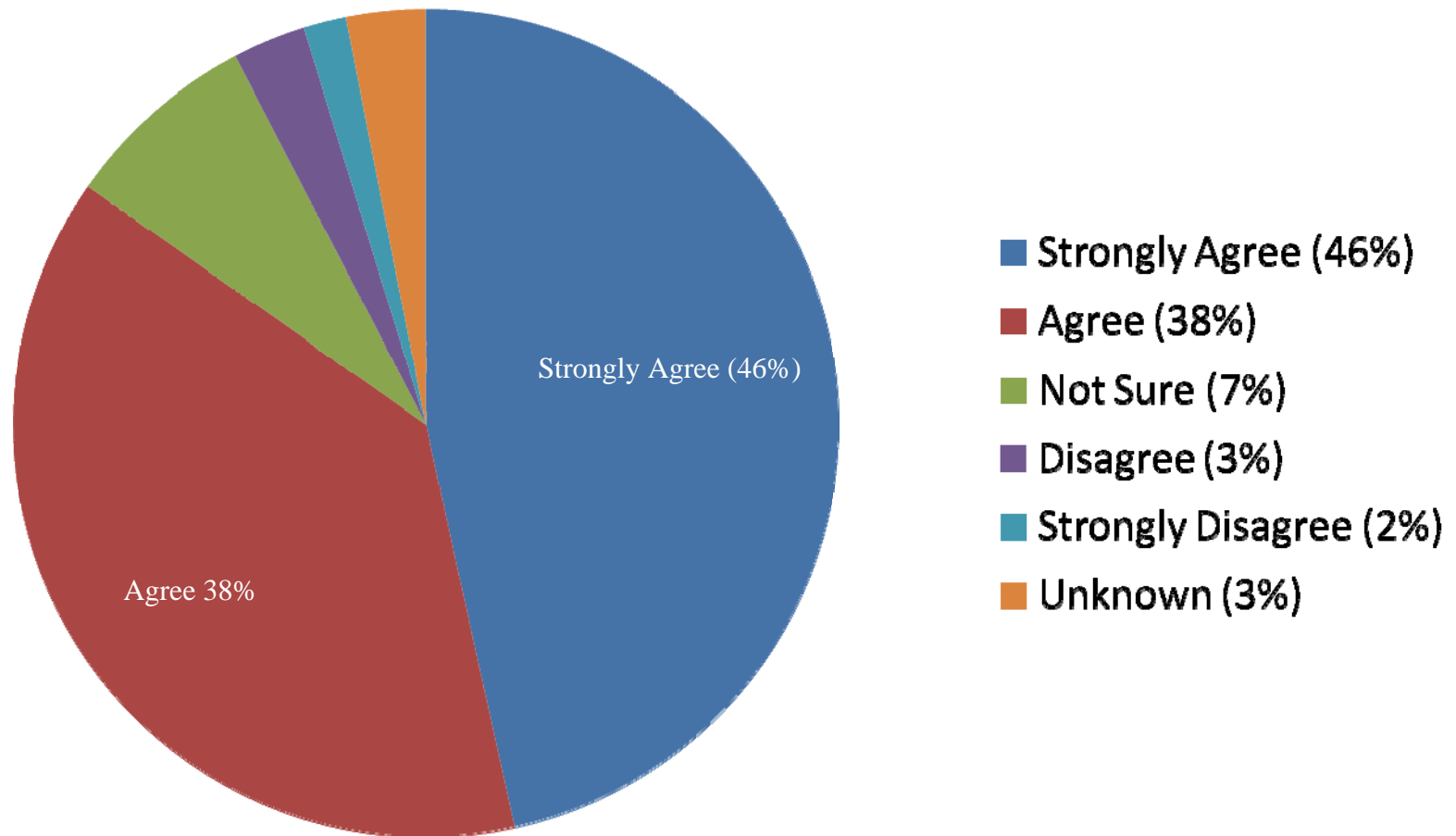
Strongly Agree/Agree = 53%

# I feel pressured by my clinician, family, or friends to participate



Strongly Agree/Agree = 4%

# I think it would be interesting

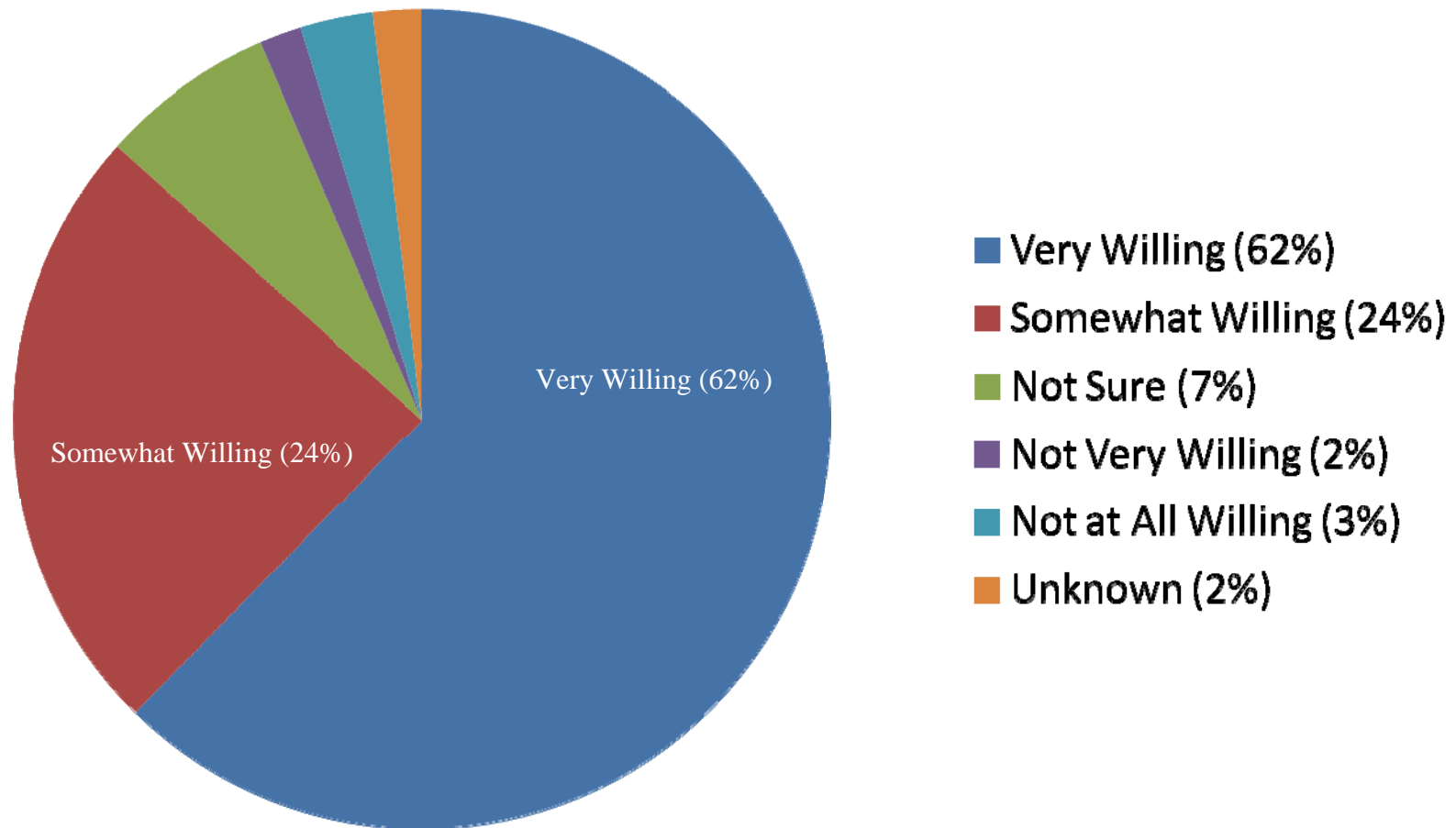


Strongly Agree/Agree = 84%

## Part 6 DNA and Research

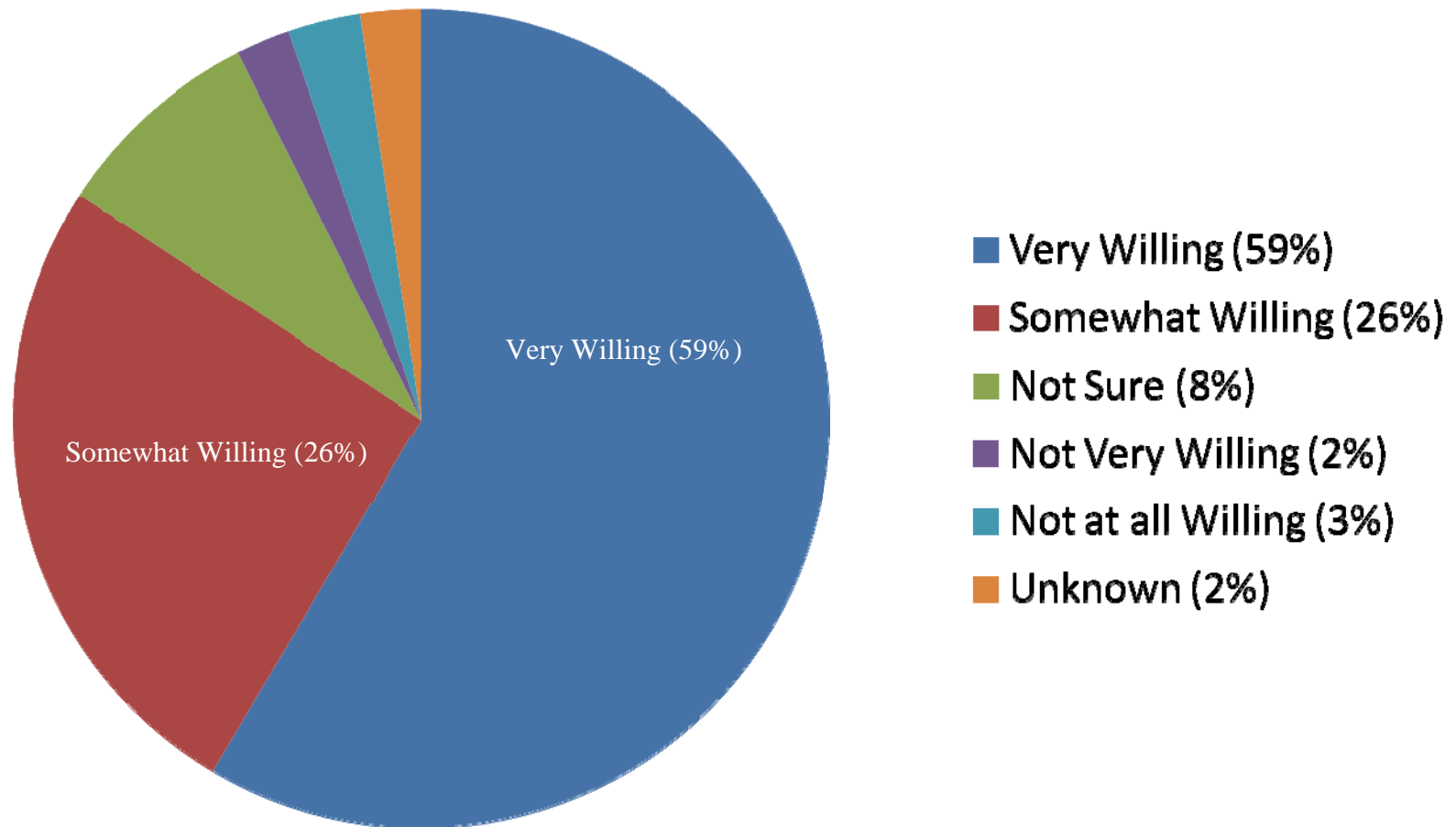
- In order to study mood disorders, DNA samples are needed from large numbers of people. This means that the researchers who collect samples might be asked to collaborate and share this information with other people or institutions who are conducting similar research studies.

If you were asked, how willing would you be to contribute DNA (from a blood test or saliva sample) for Research?



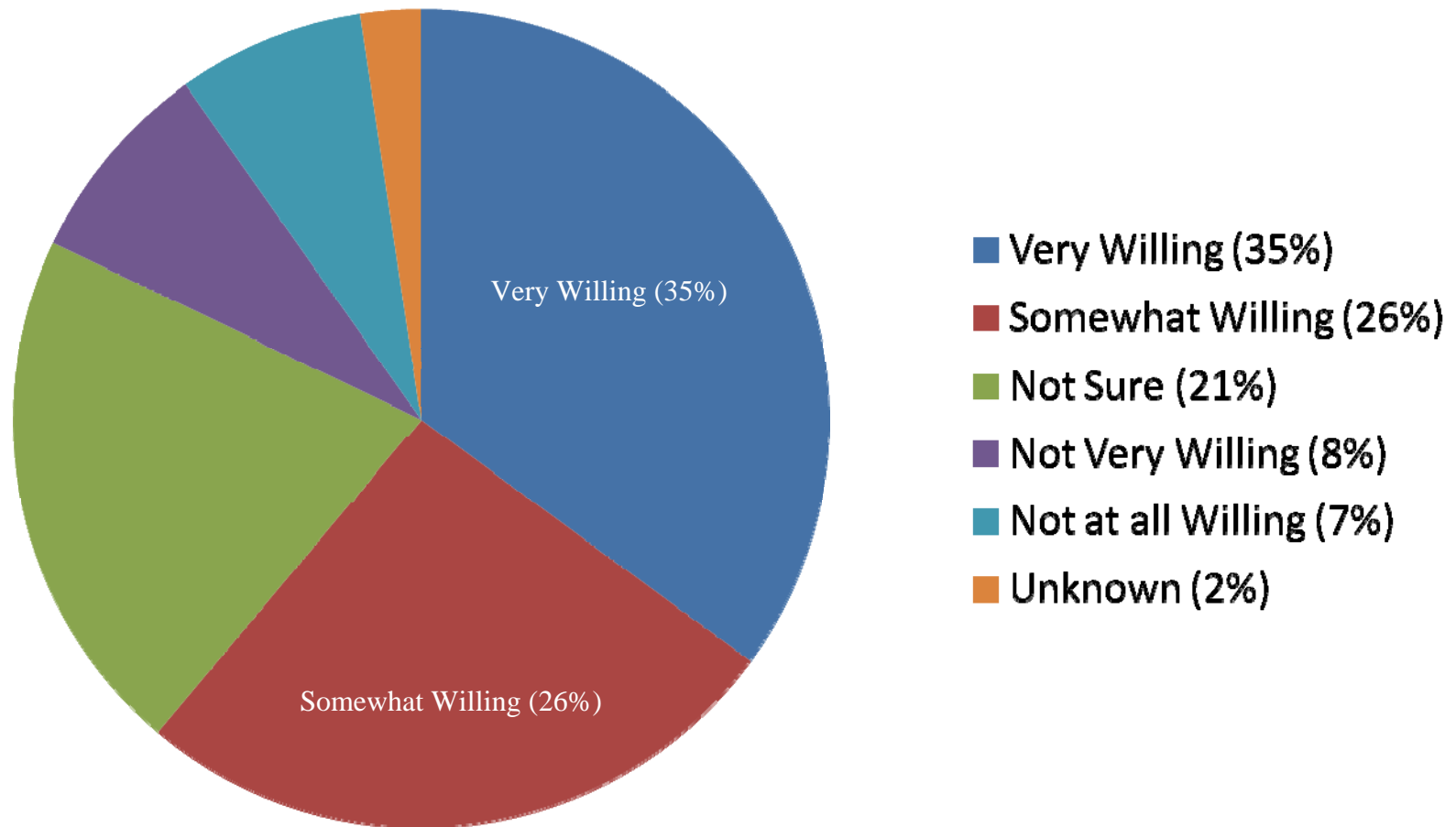
Very/Somewhat Willing = 86%

How willing would you be to share your DNA and personal information with researchers at a university or academic health center



Very/Somewhat Willing = 85%

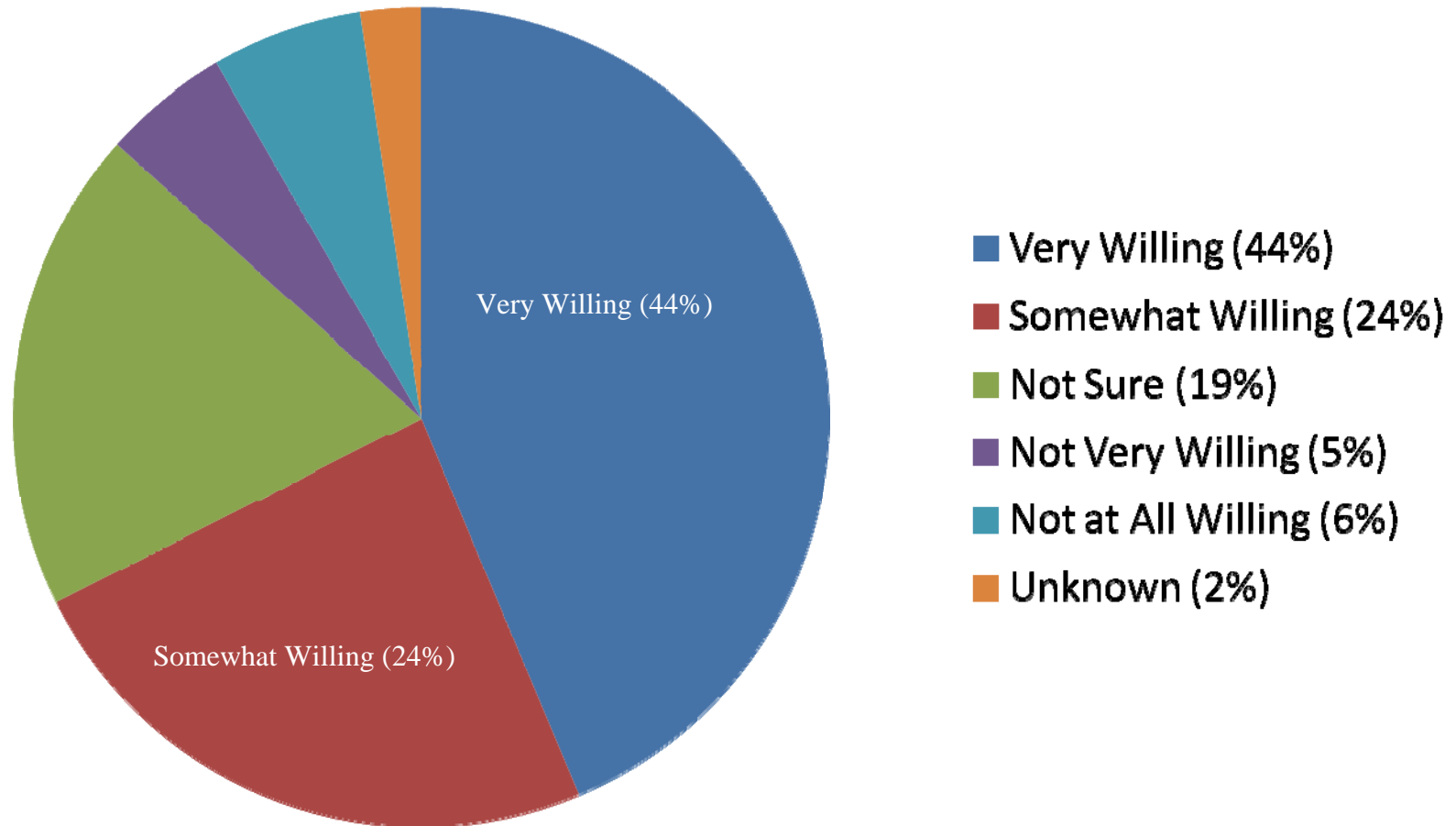
# How willing would you be to share your DNA and personal information with researchers working in the pharmaceutical industry



Very/Somewhat Willing = 61%

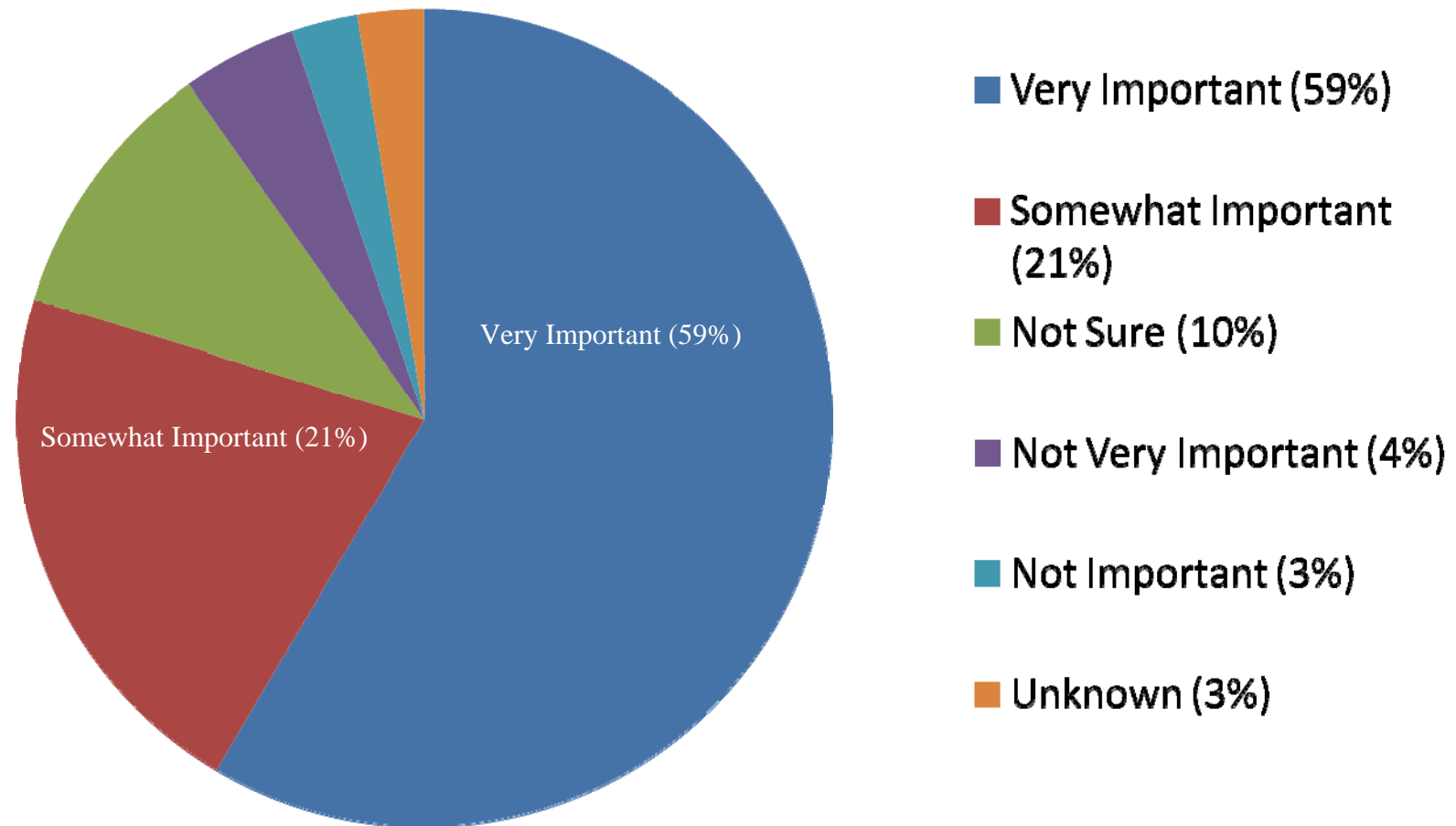


How willing would you be to share your DNA and personal information with DNA repositories stored at the National Institute of Health (NIH) sponsored by the federal government



Very/Somewhat Willing = 68%

If you participated in research that included your DNA, how important would it be to you to maintain control of your samples and personal information, including the right to withdraw from research



Very/Somewhat Important = 80%