

# American Association of Kidney Patients

May 28, 2019

*Diana Clynes, AAKP Executive Director*



# Center for Patient Engagement & Advocacy

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Engagement	Advocacy
<ul style="list-style-type: none"><li>• Appointment of patients to Federal and State advisory opportunities (Technical Evaluation Panels, etc)</li><li>• Veterans Health Initiative (VHI)</li><li>• National Ambassador Program</li><li>• Ambassador toolkits</li><li>• AAKP National Speakers Bureau</li><li>• Patient/Caregiver Certified Speakers (conferences, industry meetings, town hall meetings, trade press and media interviews)</li><li>• Social media training (web-based/in-person)</li><li>• AAKP webinars</li><li>• Membership services</li><li>• Flash surveys/questionnaires</li><li>• AAKP Medal of Excellence Program</li></ul>	<ul style="list-style-type: none"><li>• Washington, D.C. "Capitol Hill Day" Visits</li><li>• Federal agency patient visits (CMS/FDA)</li><li>• Congressional letters</li><li>• Petition campaigns</li><li>• Coordinated coalition activity</li><li>• Public policy training workshops (web-based/in-person)</li><li>• "How to Become Your Own Public Policy Advocate "(brochure)</li><li>• Patient Advocacy Training Guides (online/mobile ready – in development)</li><li>• Patient Advocate Training Certification</li><li>• Geo-targeted "Action Alerts"</li><li>• Targeted press releases</li><li>• National Patient Engagement &amp; Social Media Advocacy Awards program</li><li>• U.S. Public Service &amp; Congressional Leadership Awards Program</li></ul>

# Center for Patient Research & Education: Engaging Patients In Drug Innovation

## Center for Patient Research & Education

### Research

- **AAKP Constituent Database (continual data collection & segmentation by disease stage)**
- **AAKP Veterans Health Initiative (VHI)**
- **AAKP Social media platforms (insights)**
- **Geo-targeting for specific projects**
- **Demographic targeting for specific projects**
- **Brand Theme/Message testing**
- **Clinical Trial Awareness Campaigns**
- **Market Research (drug concept to interface/packaging)**
- **Patient Training/Information on clinical trial enrollment/participation**
- **Consults for Patient Advisory Panels/Councils**
- **Patient & Caregiver Roundtables**
- **Focus Groups (web-based/in-person)**
- **Direct patient interviews (one-on-one)**
- **Patient surveys (web-based/telephone)**
- **Flash surveys/questionnaires**
- **PCORI (all 17 kidney projects, 10+ years)**

### Education

- **AAKP "Understanding Kidney Disease" series** (print/online programs)
- **AAKP "Kidney Beginnings" series** (print/online/interactive programs)
- **AAKP Patient Plan series for managing disease** (print/online/interactive programs)
- **Nutrition Program/AAKP Delicious! Recipe Cards** (print/online/App programs)
- **aakpRENALIFE** (national magazine)
- **Kidney Beginnings** (e-newsletter)
- **Kidney Transplant Today** (e-newsletter)
- **aakpRENALFLASH** (e-newsletter)
- **Taking Dialysis Home** (e-newsletter)
- **AAKP Pediatric Kidney Kids** (e-newsletter)
- **KidneyWorks™ Employment for CKD Patients**
- **National Patient Meeting (largest in USA)**
- **Medal of Excellence Award Program**
- **HealthLines** (webinar programs – custom tailored for audiences)

# Center for Patient Research & Education

During the past 16 months, AAKP has been contacted by more than 63 companies, investment firms and major investors on questions related to trial and research related issues to provide patient preference and insights for:

- ▶ Study design/protocols
- ▶ Participant consent forms
- ▶ Study/participant materials (i.e. patient facing items such as marketing, use of appropriate language, images and graphics)
- ▶ Trial recruitment efforts
- ▶ Patient burden assessments
- ▶ Targeted patient surveys
- ▶ In-person on online video focus groups
- ▶ Cognitive interviews

In the same period, AAKP has had over 135 other contacts with government, private sector and research institutions on patient insights related to new drug/device/diagnostic regulation, reimbursement and patient consumer choice.





AAKP honors it's patient-centered mission through a strategic network of strong allies and partners – below is merely a partial listing of those who have been generous in their assistance to our mission.

## Professional & Association Allies



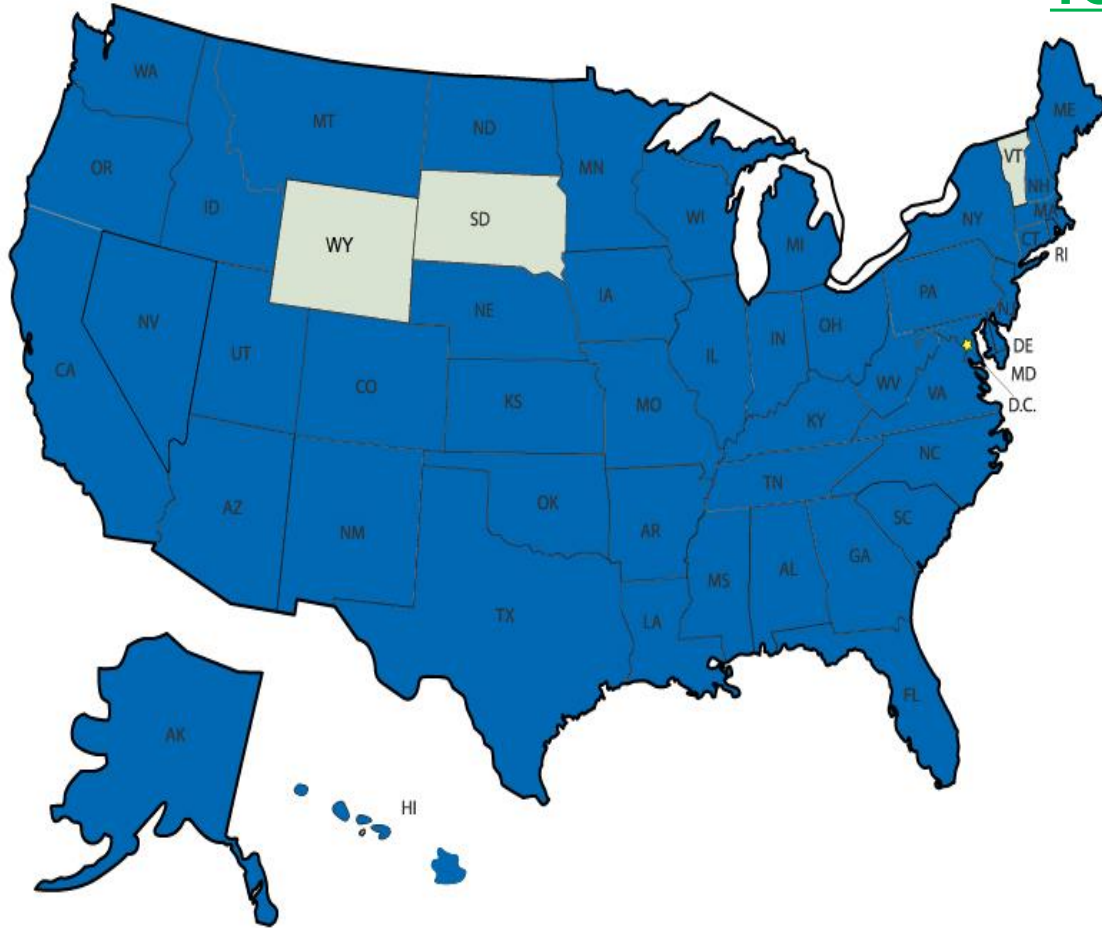
## Industry Partners





Center for Patient Engagement & Advocacy  
*National Patient Ambassador Program*

## TOP PATIENT INFLUENCERS IN USA



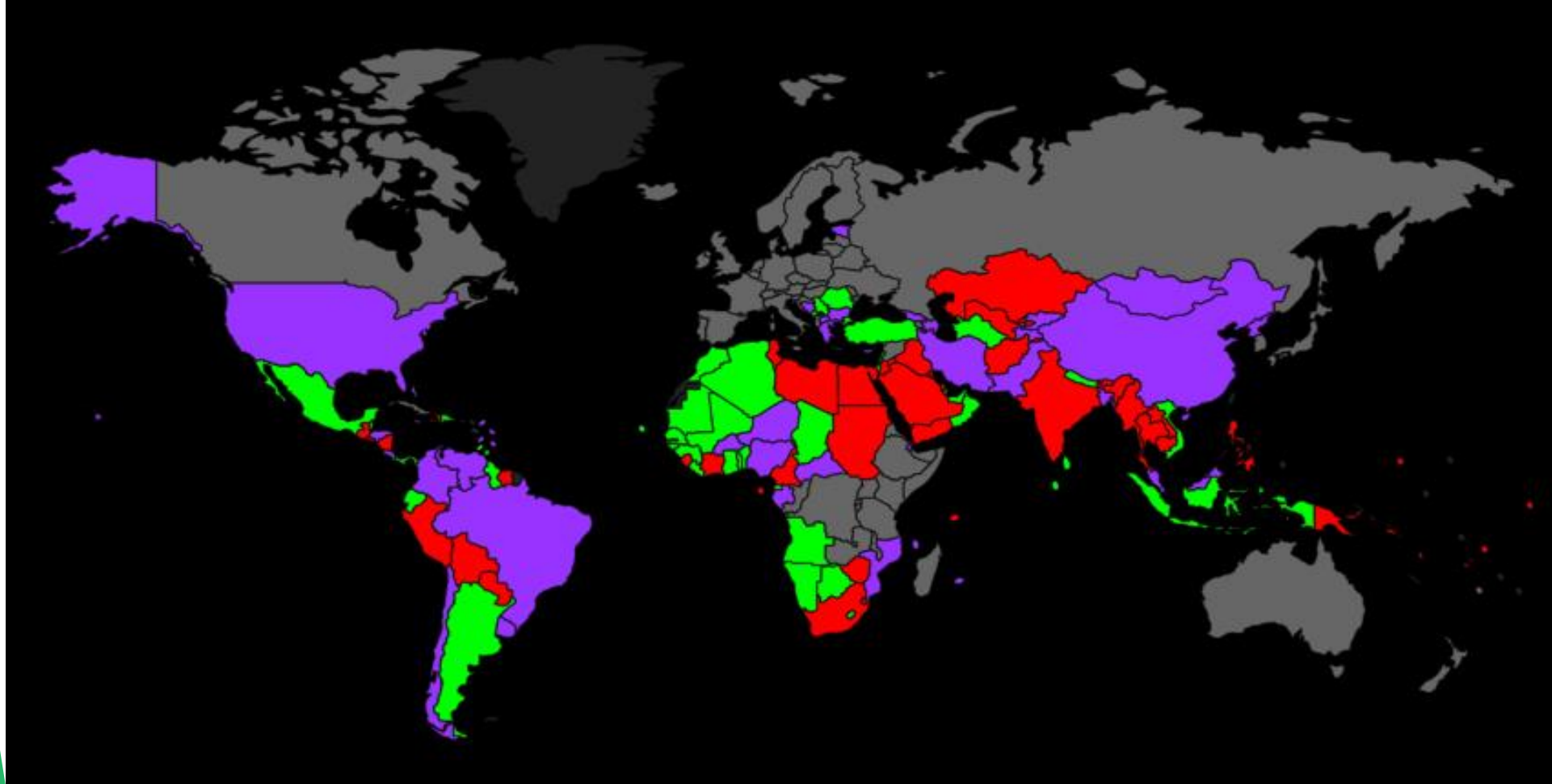
## Since 2017 Creation

- ▶ **120+ Ambassadors in 47 States, plus D.C.**
- ▶ **Highly informed kidney patients**
- ▶ **Strong social media networks**
- ▶ **Frequent visits to Capitol Hill**
- ▶ **Serve on Federal advisory boards**
- ▶ **High clinical trial experience**

**2020**

- **400 Every Congressional District**

# Worldwide Kidney Disease: *Death Rate Per 100,000 (age standardized)*



# AAKP Global Ambassadors

## AAKP Launch:

United Nations, May 2018

## Inaugural Global Summit:

AAKP/George Washington  
University School of Medicine,  
May 21-23, 2019

*England, Ireland, India,  
Kenya, South Africa,  
Slovenia, Denmark,  
Canada, Mexico, Japan,  
Australia...*

**25 Countries by 2020**





# Inaugural Global Summit: Innovations in Patient-Centered Kidney Care *(Highlights)*

- ▶ Total number of presentations: 35
- ▶ Number of organizations represented: 24
- ▶ Countries represented by speakers: 5
- ▶ Total number of registered attendees: 190+
- ▶ Number of sessions: 9
- ▶ Sponsored symposium: 1
- ▶ Live Stream: ***South Korea, Malaysia, Egypt, Azerbaijan, Philippines, Singapore, Netherlands, India, Nigeria, United Arab Emirates, Saudi Arabia, South Africa, Chile, Zambia, Australia, Sweden France, Germany, Ireland, Canada, Columbia, the United Kingdom, China and Russia.***

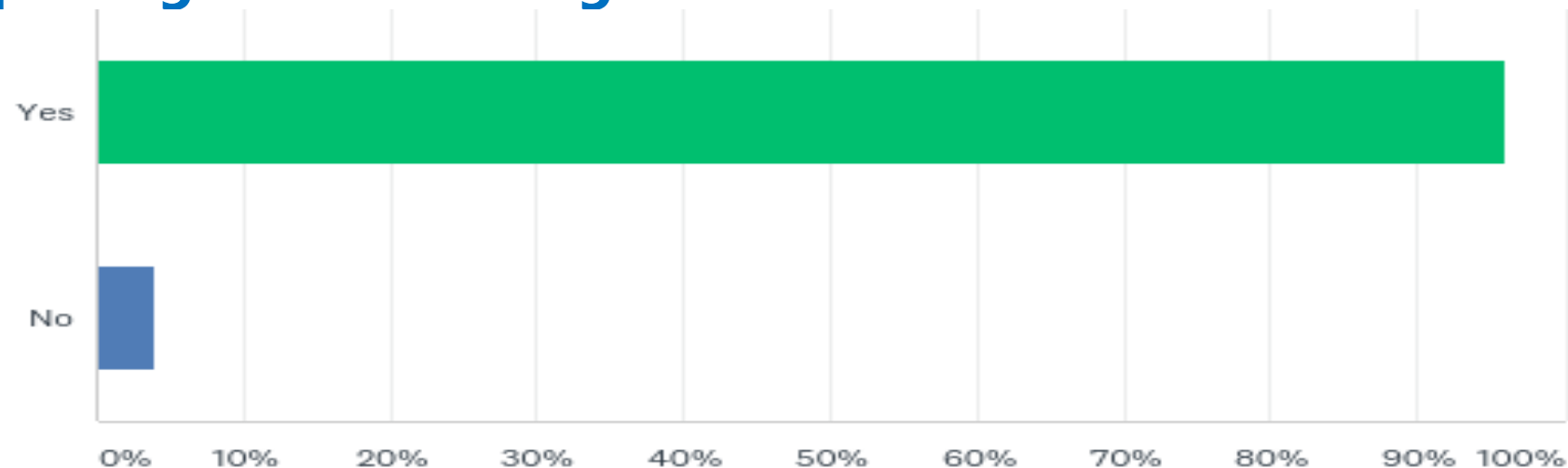
# AAKP Flash Survey: CKD Patient Insights Needed on Clinical Trial Participation



Powered by  SurveyMonkey®

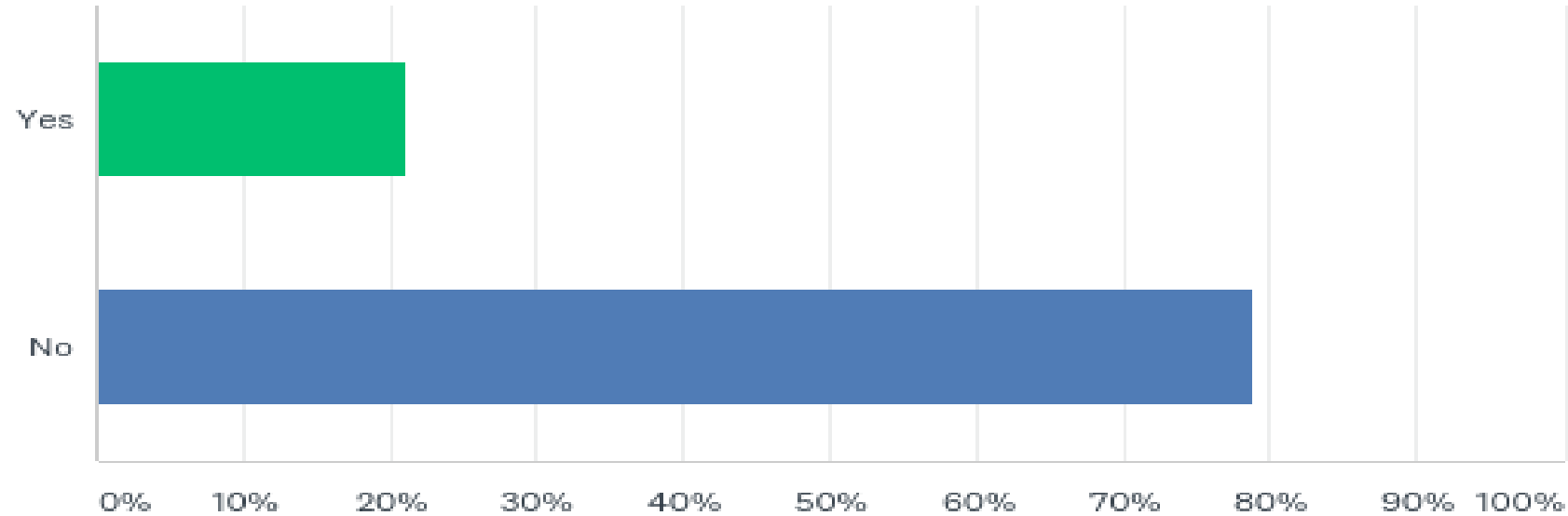
## AAKP HISTORIC OBSERVATION:

When **ASKED** and **RESPECTED**, kidney patients will honor the ideal of placing their suffering in service to others...



MAY 4/5/2019 FLASH PUSH POLL (FREE MARKET): As an individual that suffers from a chronic disease (chronic kidney disease), if you felt your insights were valued and used to improve/advance clinical trials and drug development, would you help companies develop more products/treatments to help fellow patients and those yet to be diagnosed?

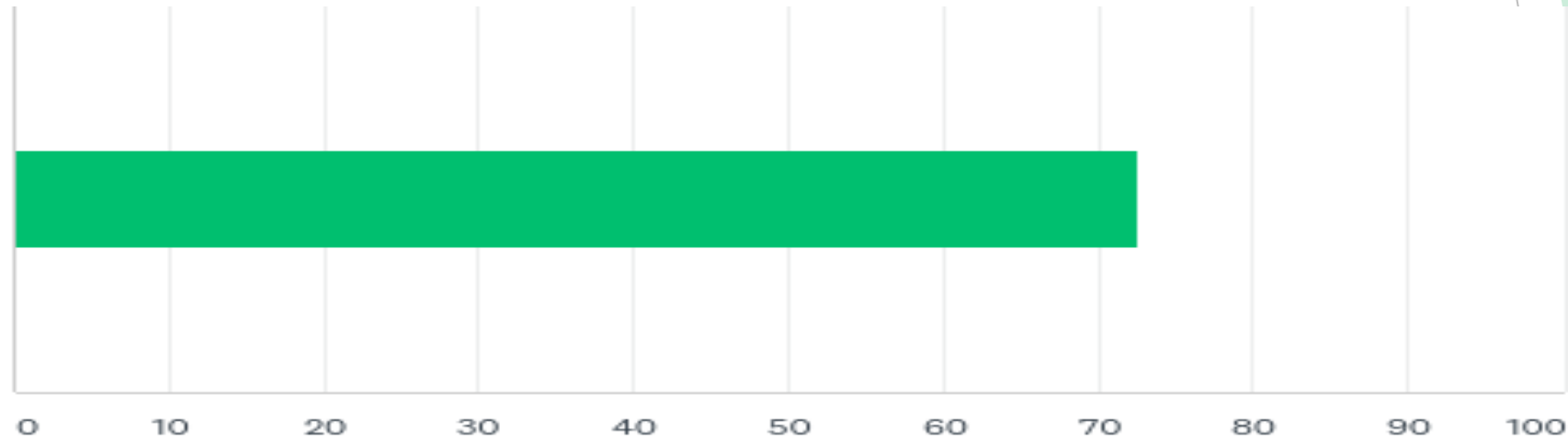
# Have you ever been asked to participate in a clinical research trial?





# Rate your experience participating in the clinical trial:

*(those who answered "yes, I have been asked to participate in a trial")*



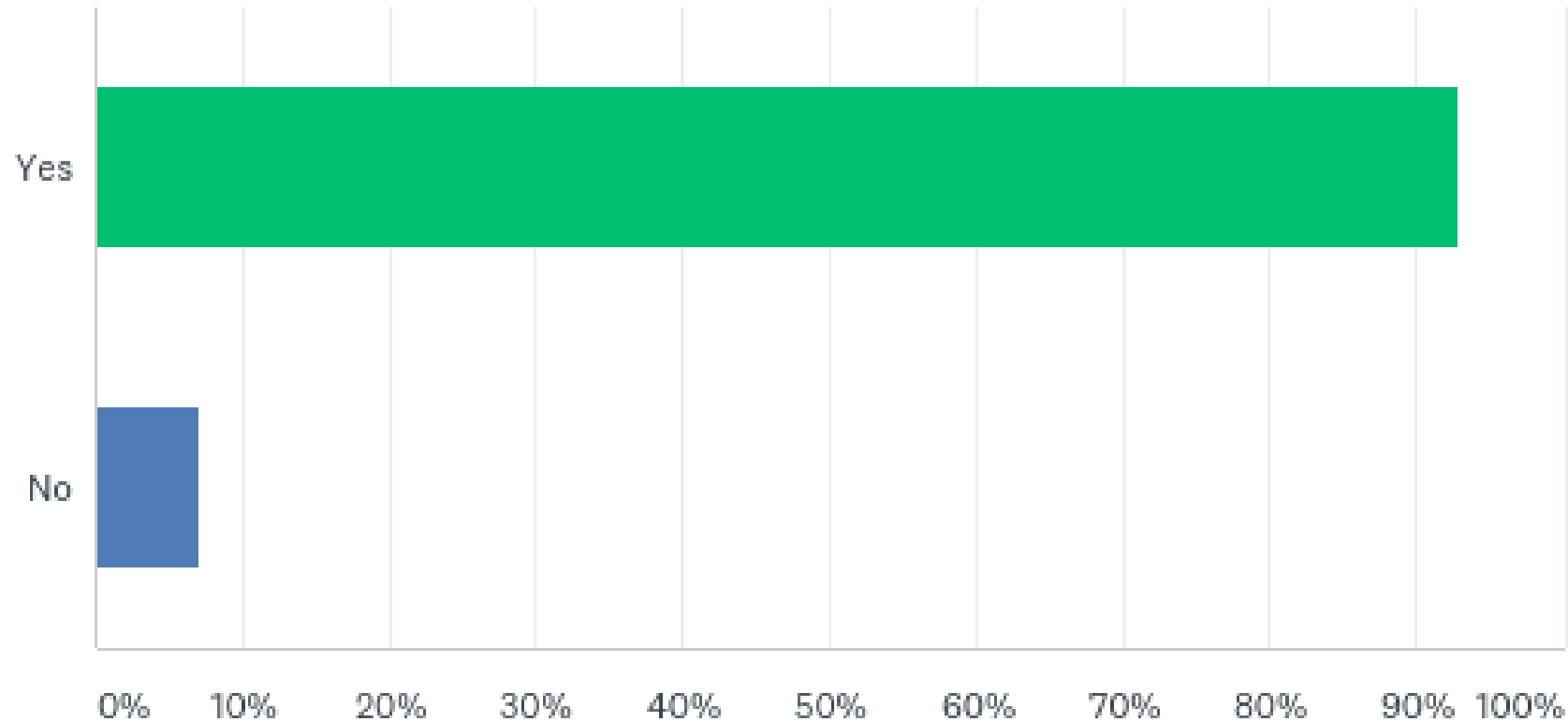
negative

neutral

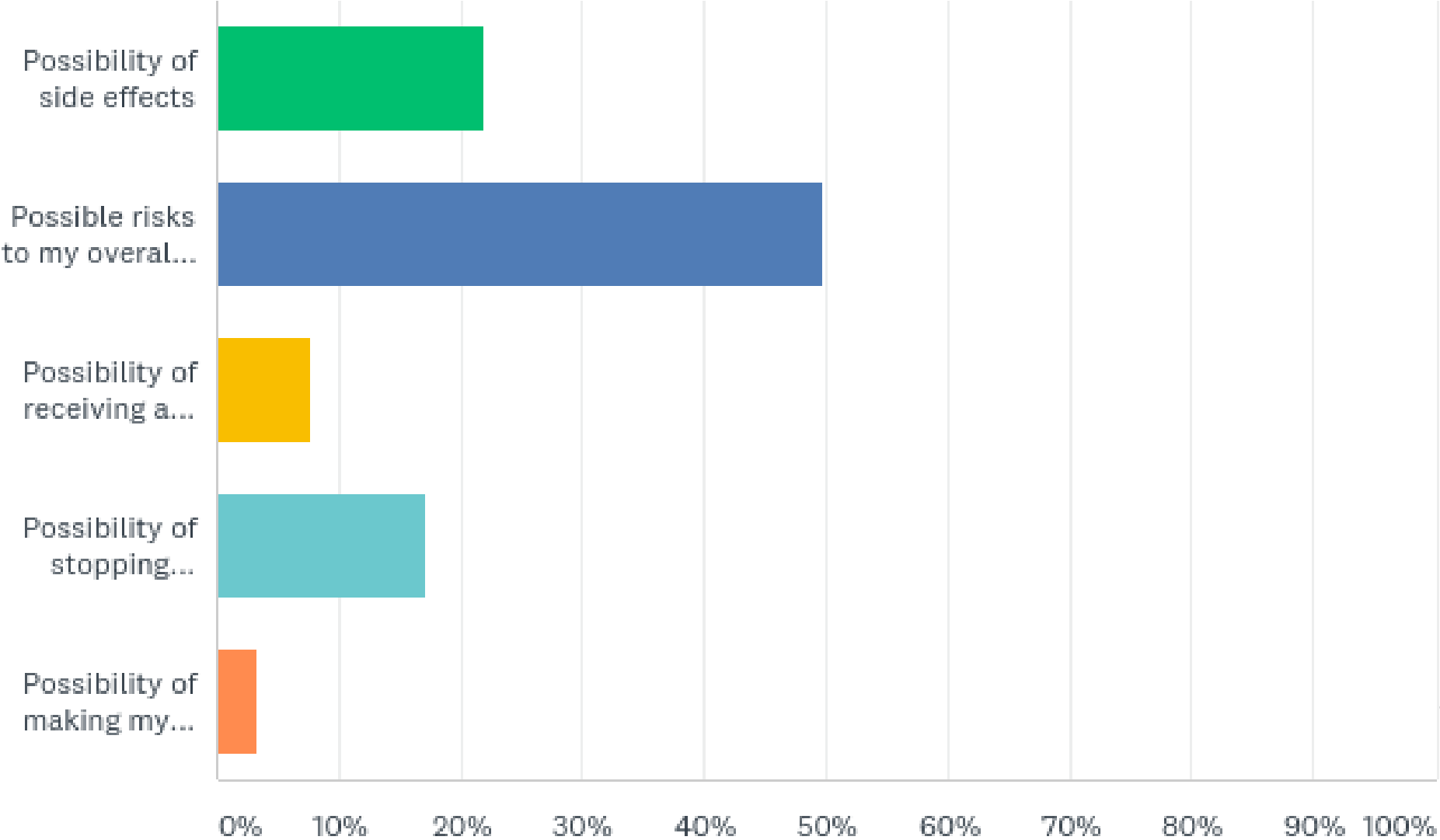
positive

# Would you participate in a future clinical trial again?

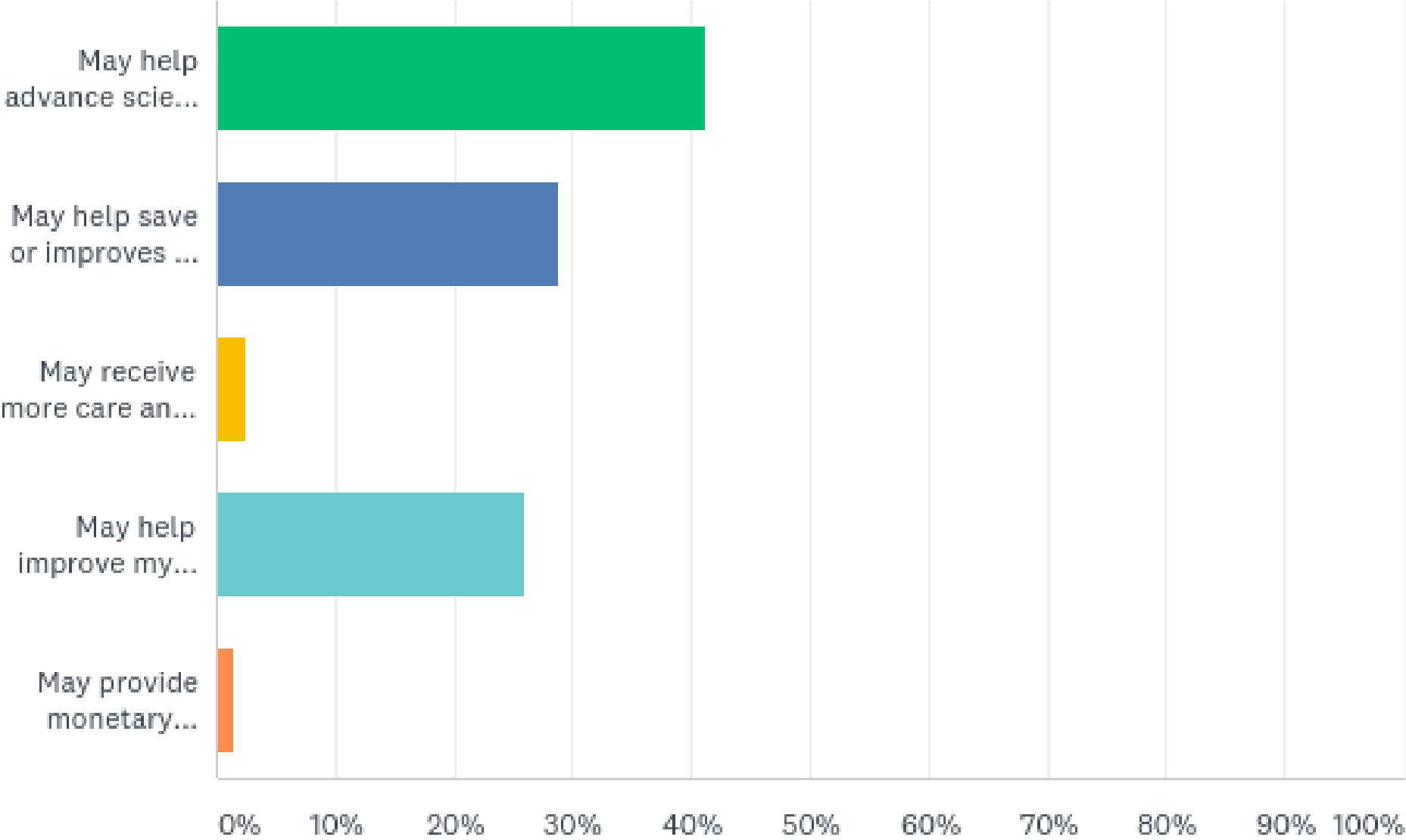
*(those who answered Q2 "yes, I have been asked to participate in a trial")*



Whether you have participated in a clinical trial or not, which ONE of the following do you consider to be the greatest risk of participating in a clinical research study?

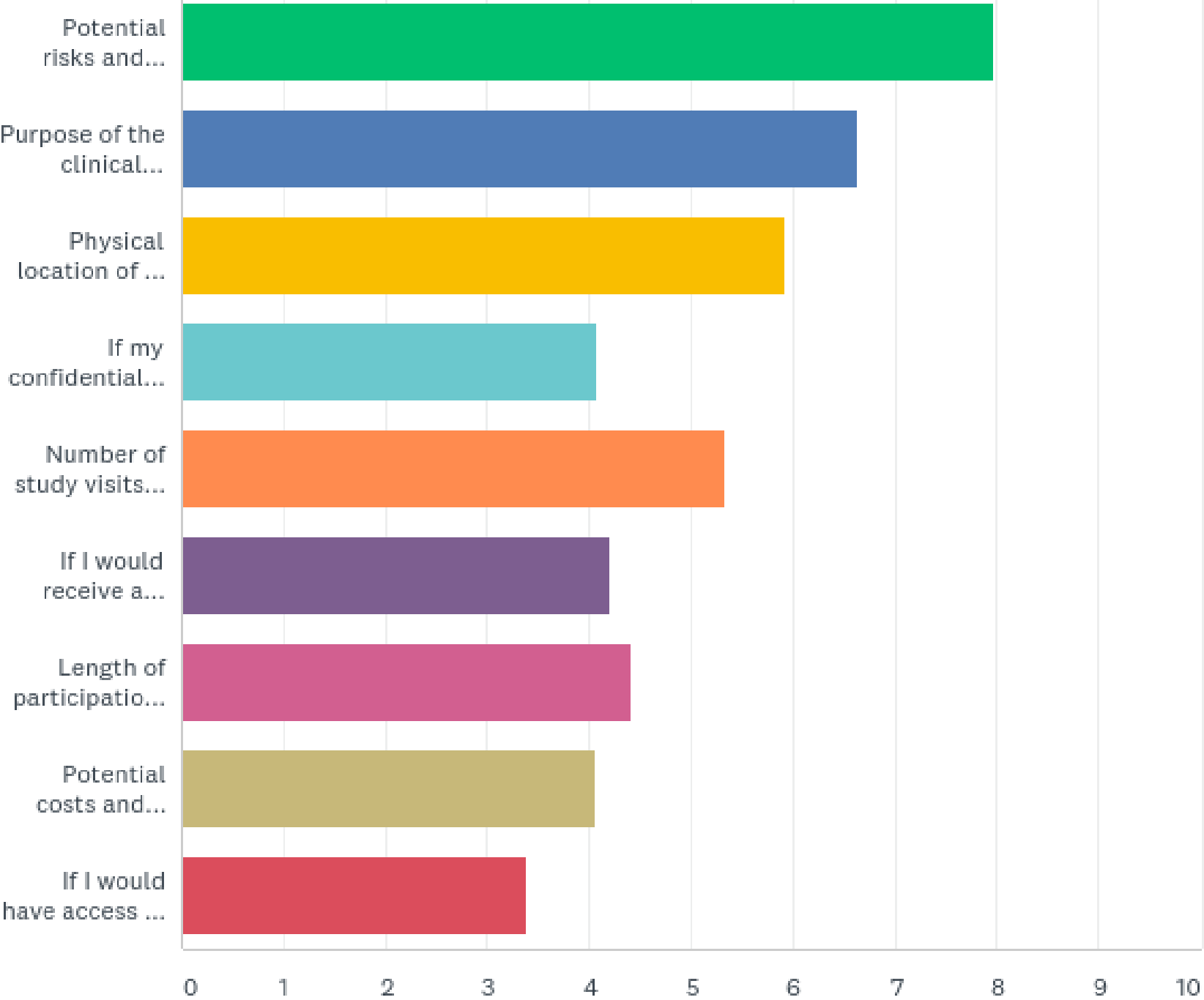


Whether you have participated in a clinical trial or not, which ONE of the following do you consider to be the greatest benefit of participating in a clinical research study?

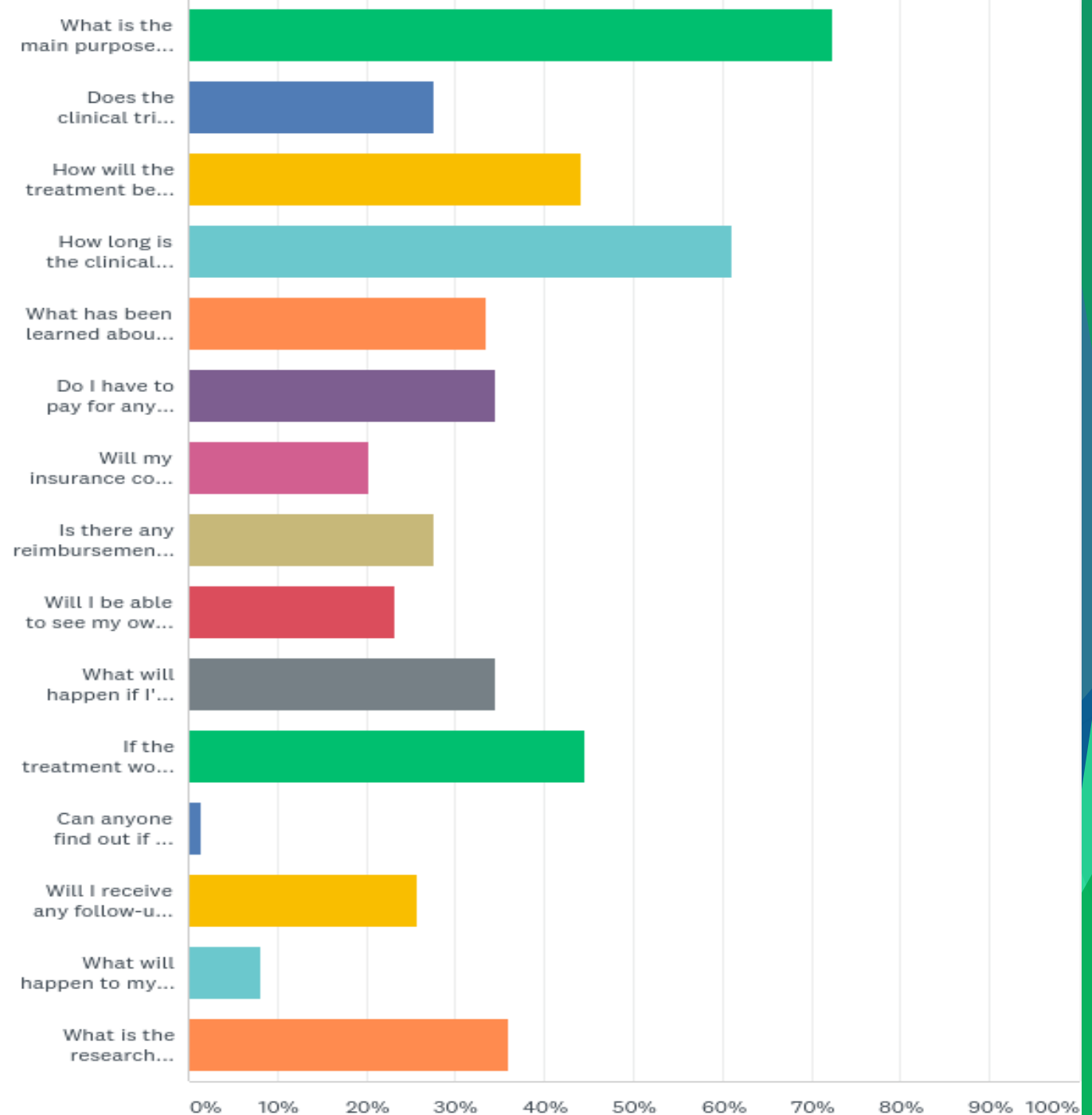




From the list below, please rate (from 1 to 9 with 1 being most important to you and 9 being least important to you), the most important information influencing your decision to participate in a clinical trial on drug development:



Please select the top FIVE questions most important to you that you would ask before participating in a clinical research study?



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