



Stanford | MEDICINE

## Spectrum

Center for Clinical and Translational Research and Education

# Research Participant Engagement Program

[EngageParticipants@stanford.edu](mailto:EngageParticipants@stanford.edu)

June 2023

*Stanford's Research Participant Engagement Program is supported by the Stanford CTSA Award Number UL1TR003142 from the National Center for Advancing Translational Science (NCATS), a component of the National Institutes of Health. PI: Ruth O'Hara*

<https://med.stanford.edu/spectrum/researcher-resources/participant-engagement.html>



# Problem Statement



Majority of studies don't draw enough participants!

- Participant recruitment is one of the greatest challenges to successful clinical research. Stanford has needed tools and processes that can significantly increase participation while ensuring patient privacy and data security.
- Clinical trials also suffer from a lack of diversity and inclusion. Stanford is seeking ways to adequately represent diverse populations in clinical studies.

# Participant Engagement Team

Katherine Connors, Associate Director

Andrea Bolanos, Program Coordinator

Maya Berdichesky, Trial Innovation Network Hub Manager



John Maul, PEP Project Manager

Todd Ferris, Anthea Buchin, Research Systems

Sijo Thomas, Tricia Ning, Children's Research Informatics



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Technology & Digital Solutions  
*Stanford Health Care and School of Medicine*



**Stanford**  
Children's Health

Lucile Packard  
Children's Hospital  
**Stanford**

Faculty Advisors:

Aruna Subramanian



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Infectious Diseases  
*Department of Medicine*

Anisha Patel



**STANFORD**  
**MATERNAL & CHILD HEALTH**  
**RESEARCH INSTITUTE**



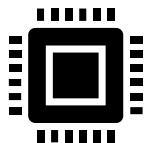
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# Research Participant Engagement Program

*provide resources and tools... with a focus on engaging participants as partners in research*



- Participant recruitment **consultations** with study teams



- Participant Engagement Platform (PEP) **honest broker study invitations**
  - Direct Email, Children’s Epic MyChart, Postal Mail, and now... SHC Epic MyHealth



- **Beyond Stanford** outreach: social media resources, tabling events, and our Stanford Research Registry– REDCap database of ~11K research volunteers



- **Community engagement** guidance and referrals to our Office of Community Engagement, Community Advisory Board (CAB) for Clinical Research, and Maternal & Child Health Community-Engaged Research



- Guidance about other resources at Stanford and externally, such as the **CTSA Trial Innovation Network**

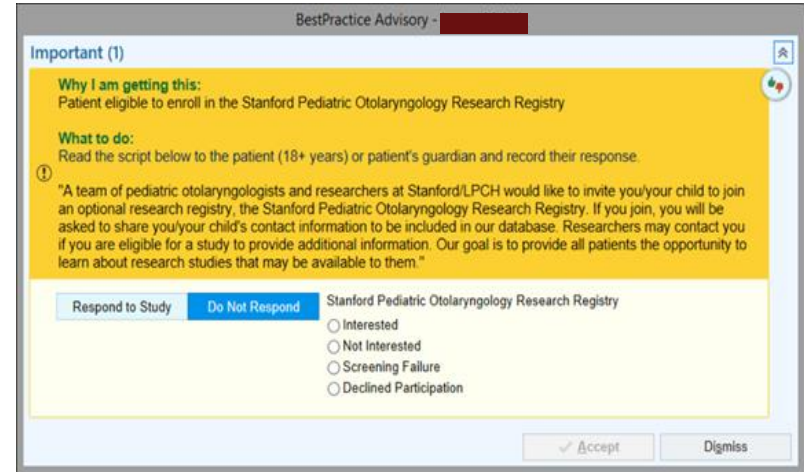
*See resources including “Recruitment Strategizing Worksheet” here:*

<https://med.stanford.edu/spectrum/researcher-resources/participant-engagement/engagement-tips-and-resources.html>

# Additional Children's Epic Patient Engagement Resources

## Best Practice Alerts (BPAs)

- Pop-up appears for Provider during patient visit, indicating patient may be eligible for a study. Provider notifies Patient and if Patient interested, a MyChart message (perhaps with screening link) can be sent, and/or Provider can share a QR code appearing in the Alert.



## “Bulk MyChart” study invitations

- Study invitation is sent from Clinic/Provider (vs honest broker) to all likely eligible patients within clinic
  - E.g.: “Sincerely, Dr. <name> and your Pediatric Diabetes Care Team”
- Requires documented clinic leadership endorsement
- May include PCHA/Tri-Valley patients

# IRB Recruitment Guidance

- <https://researchcompliance.stanford.edu/panels/hs/policies/guidances>  
See “General guidance on participant recruitment”

Stanford University HRPP Policy Guidance	<b>Recruitment</b>	GUI-33 1/2
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## **Initial Contact with Potential Participants**

- When there has been no previous contact with a potential participant, care must be taken to ensure that the potential participant understands how the researcher acquired private information about them, and that the information was obtained in a legitimate manner. For example, if the participant was referred to the researcher by the individual’s physician or other treating health care professional, the researcher can cite that referral as a reason for the contact.
- Extreme caution should be exercised when potential participants are identified through chart reviews or through STRIDE under a Waiver of HIPAA Authorization for recruitment, as these avenues to PHI are less familiar to participants, and can lead to complaints to the Privacy Office when misconstrued as illegal use of PHI. In these cases, the researcher might first consider sending a letter to participants, signed by a health care provider or hospital department that would be recognizable to the potential participant, and providing a telephone number or other means that the potential subject can use to verify that the study constitutes Stanford research.

# Outreach Methods – What is Honest Broker

	Pros	Cons
<b>Current Methods</b> <ul style="list-style-type: none"><li>• PI/Physician contact</li><li>• Physician referrals</li><li>• Clinic visit</li><li>• Flyers</li><li>• Community Events</li></ul>	<ul style="list-style-type: none"><li>• Often promotes physician-patient relationship, trusted advisor, coordinator of care</li></ul>	<ul style="list-style-type: none"><li>• Time intensive for physicians and study team</li><li>• Not scalable for large outreach efforts</li><li>• Not applicable for all studies</li></ul>
<b>Additional Method – “Honest Broker”</b> <ul style="list-style-type: none"><li>• An honest broker (trusted 3rd party) conducts outreach on behalf of the study team/investigators</li></ul>	<ul style="list-style-type: none"><li>• PHI not shared with study team until patient expresses interest; Privacy and Compliance</li><li>• Service provided following SOP and recruitment best practices</li><li>• Access to data and tools support scalable, large outreach efforts</li></ul>	<ul style="list-style-type: none"><li>• Does not leverage treating relationship</li></ul>

# Participant Engagement Intake



- Contact [EngageParticipants@stanford.edu](mailto:EngageParticipants@stanford.edu)
- Review:
  - Study synopsis, IRB # if available
  - Inclusion/exclusion criteria
  - Timeline; Enrollment goal and status
  - If applicable, recruitment strategies tried and recruitment materials/language
  - Onboarding capacity = # potential participants study team can screen/schedule in 24-48 hours
  - Other relevant information, such as compensation
- Discuss recruitment strategies and available services.
  - Confirm **OnCore** registration – **Per Participant Accrual**
  - Provide guidance for IRB modifications, STARR cohort creation, Epic registration



# Study Team Order of Procedures

1

Consult with RPEP team to identify applicable honest broker services

2

OnCore study registration (Per Participant Accrual)

Create your StudyPages workspace

Create study invitations with RPEP team review

Confirm/Obtain Epic study registration

Confirm/Obtain Epic access

3

Obtain IRB approval

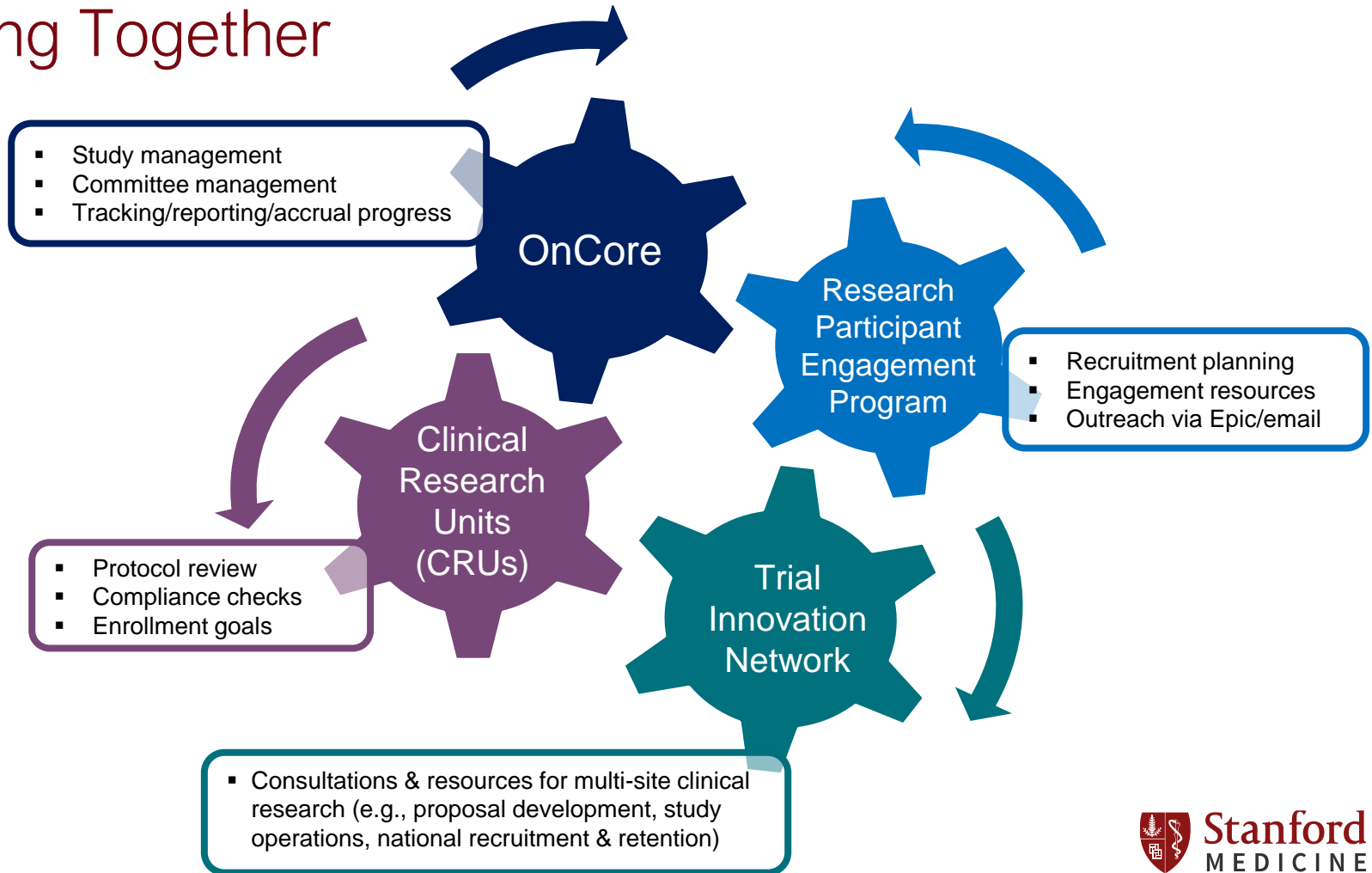
Create STARR cohort and save to Public Library

Update OnCore status to "Open to Accrual"






4

Notify RPEP team when level 3 components are complete










# Working Together




DEMOGRAPHICS

-  Current Age
-  Gender
-  Race
-  Ethnicity
-  Language


CLINICAL EVENTS

-  Diagnosis
-  Procedure
-  Laboratory Test
-  Drug Ingredient/Brand
-  Drug Class
-  Clinical Documents
-  Encounter
-  Admission
-  Vital Status

TEMPORAL CONSTRAINTS

-  Pair of Events

BIOSPECIMENS

-  Precision Health Biobank

# Stanford Research Repository (STARR) Tools

- <https://med.stanford.edu/starr-tools.html>
- Stanford Medicine's approved resource for working with clinical data for research purposes
- Pulls EHR data from both hospitals and ancillary clinics daily
- The home of two web tools:
  - **Cohort Discovery**  
Pre-IRB, de-identified data, patient counts based on criteria, including key words from clinical documents/notes
  - **Chart Review** (self-provisioned or custom with Research Informatics Center (RIC))  
Requires IRB/Privacy approval
- Can only outreach to own patients\*. Enter honest broker!

# Participant Engagement Platform (PEP)

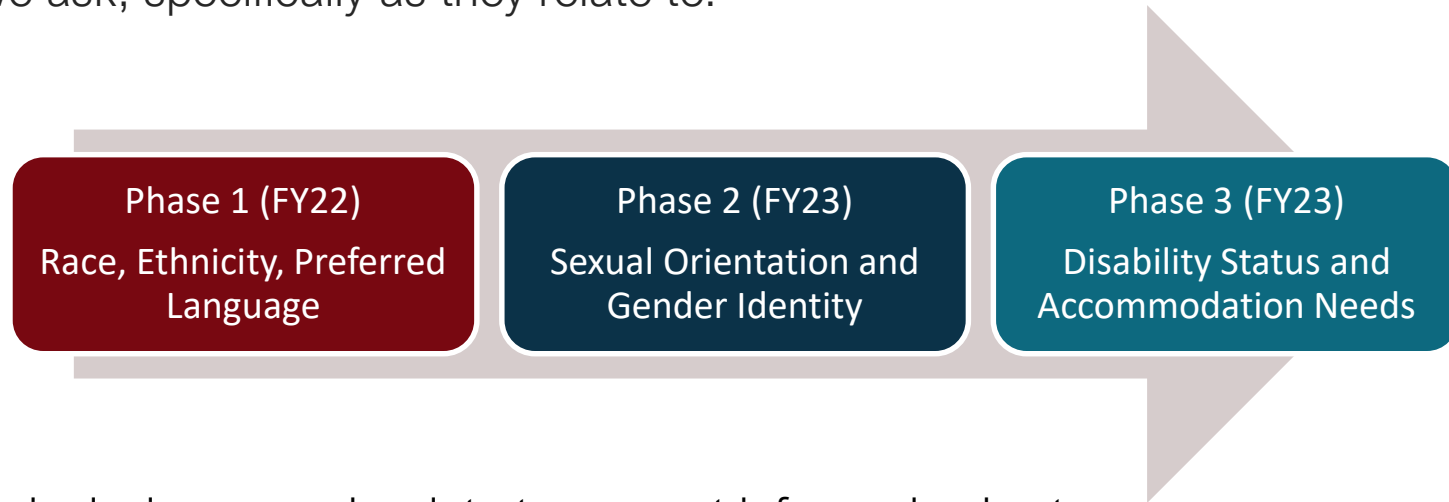


- Our PEP workflow identifies potential participants by applying the study inclusion/exclusion criteria to Stanford's STARR database.
- If study team wishes to use Epic MyChart/MyHealth, Direct Email, and/or Postal Mail, PEP determines best method of contact based on participants' Epic (MyChart/MyHealth account/usage), email, or postal mail address availability.
- Participant Engagement team serves as the **Honest Broker** through the PEP
- PEP tracks age/race/sex metrics. We can modify outreach to increase representation.



# Better Data for Diversity, Equity, Inclusion

**We Ask Because We Care:** A Stanford Medicine initiative to capture and include more precise demographic questions and educate patients, providers, and staff on why we ask, specifically as they relate to:



More inclusive, granular data to support informed cohort evaluation and study design

# New PEP feature: Demographic Optimization

- To help diversify participant populations, target percentages for race, ethnicity, and sex categories can be entered into PEP.
- When preparing outreach, PEP will automatically continue to prioritize the underrepresented demographics, recalibrated for each wave, until the percentage goals are met.
- Demographics to be tracked at the current time are:

Race	Ethnicity	Sex
<ul style="list-style-type: none"><li>• White</li><li>• Black/African American</li><li>• Asian</li><li>• Native American/Alaskan</li><li>• Pacific Islanders</li><li>• Two or more/Other</li></ul>	<ul style="list-style-type: none"><li>• Hispanic</li><li>• Non-Hispanic</li><li>• Unknown</li></ul>	<ul style="list-style-type: none"><li>• Male</li><li>• Female</li><li>• Other/Unknown</li></ul>

- Additional categories such as age ranges, pregnancy status, disabilities, SOGI (sexual orientation and gender identity), and comprehensive racial breakdown will be added in next phases.

# Participant Engagement Outreach



## Participant Engagement Platform (PEP) honest broker services

Stanford  
patients  
(STARR)

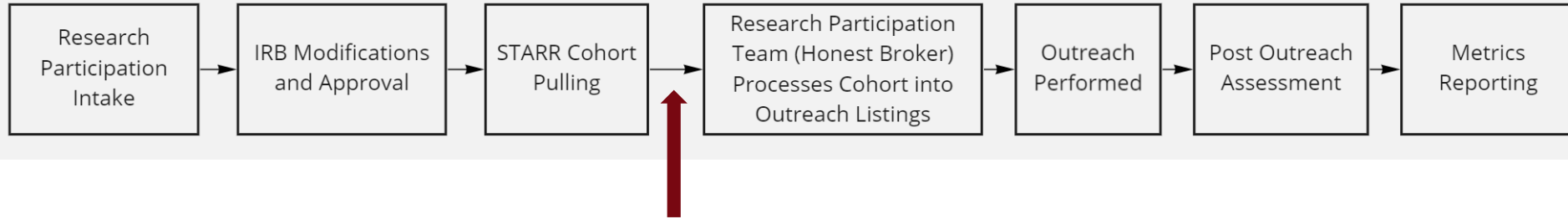
1. Direct Email using Qualtrics for studies including healthy controls – Feb 2020
2. Epic MyChart (Children's) secure portal – Mar 2020
3. Epic MyHealth (SHC) secure portal – Sept 2022
4. Other Honest Broker services:
  - Postal Mail – May 2020
  - Phone Calls (“Deputized” Honest Broker for COVID) – May 2021
  - Text Messages – 2024

Beyond  
Stanford

1. Research Registry – Apr 2020
2. Social Media

\*Registry is an “opt-in” model

# Participation Engagement Platform workflow



- Pulls Cohorts from Stanford's Electronic Health Record research database (**STARR**)
- Validates study is Open to Accrual in **OnCore** prior to outreach
- Screens outreach against on study participants in OnCore and from a global **opt-out list** to prevent inappropriate outreach
- Identifies best outreach **channel** (Epic MyChart/MyHealth, Direct Email, Postal Mail)
- Generates system friendly participant listing to be used by outreach software (e.g. Qualtrics)
- Tracks the outreach progress for studies



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Research Office

Research Participation Program

*A note from the team: You are receiving this message because you or your family is cared for at Stanford HealthCare or Stanford Children's Hospital. This message comes from the Stanford's Research Participation Program. Stanford University's Institutional Review Board (IRB) approved this way of finding people to join the study. The IRB is a group that protect the rights and welfare of people in research studies. This message meets state and federal rules for research studies. Your contact information has not been shared with any doctor or member of the research team.*

We are writing to invite you to participate in a new research study. We are looking for participants 18 years and older who have been diagnosed with glaucoma (or possible glaucoma), as well as patients who have no glaucoma or other significant eye diseases for comparison.

**Name of Project:**

Glaucoma Pathways

**What we are trying to do:**

The study is focused on finding new ways to detect and monitor glaucoma and its treatments.

**Who is in charge of the project:**

Dr. Jeffrey Goldberg will be in charge of this project. Dr. Goldberg is a Professor and Chair in the Department of Ophthalmology at Stanford Medicine. He is very excited to continue to partner with families and individuals like you.

**What we would need from you:**

- One 1-2 hour visit at Byers Eye Institute and the Spencer Center for Vision Research (Palo Alto, CA), which may include:
  - vision exams
  - non-invasive pictures of your eyes
  - non-invasive brainwave recording
  - If you have done any of the above as part of your recent clinical care, you do not have to repeat them.

**No treatment or medications will be given as part of this study.**

**What you get for your time:**

If you are eligible, upon completion of your visit, we will reimburse you \$20 per hour.

**Would you like to learn more?**

Yes.

I am Interested.

No.

I am not interested.

**Where you can learn more:**

If you would like to learn about other research studies, please visit the [Stanford Clinical Trials Website](#). We look forward to talking to you soon.

Sincerely,

The [Stanford Research Participation Program](#), on behalf of Dr. Jeffrey Goldberg

If you would prefer not to receive email correspondence from Stanford's Research Participation Program, you can [Unsubscribe](#) or contact us at [joinresearch@stanford.edu](mailto:joinresearch@stanford.edu) or by phone 650-497-3612. For Participant's rights questions, contact 1-866-680-2906. Reference IRB#: 38931. Invitation email generated on December 9, 2020 12:47:48 PST

## "Email tickler" Notification of MyChart message:

Sender: DONOTREPLY@STANFORDCHILDRENS.ORG

Email subject: New Research Opportunity

Hello <first name last name>,

["You have"] a new message regarding a research opportunity. Please respond by logging into your [MyChart](#) account. If you do not want to receive emails like this in the future, you can update your participation preferences after logging in.

Healthy regards,

Stanford Children's MyChart Online Care Team

<LOG IN NOW>

\*\*This is an automated message. Please do not reply to this [message](#).\*\*



Girl-Sally



Health



Visits



Messaging



Billing



Research



Profile

Ver en Español

ZZ Test Red Zztest  
Log Out

Welcome (Girl-Sally)



Schedule your Flu Shot.



Enter your e-mail address to start receiving notifications about new information in your MyChart account.



Join research studies for which you are a good candidate. You have a new study to review.



View test results



Ask a question



Refill medications



Pay My Bill

To Do [🔗](#)

Overdue health reminders

Care Team

## Research Studies



Welcome!

### Stanford Medicine MyChart Research

Research studies help medical teams discover new treatments for patients.

The following Stanford Medicine studies may be of interest to you or related to your health and health care. These are being suggested to you based on an automated search. Your contact information has not been shared with any research teams.

If you have questions, you can contact the [Research Participation](#) Team at [joinresearch@stanford.edu](mailto:joinresearch@stanford.edu).

**Please select your preference for receiving MyChart research invitations from the Research Participation Team:**

### Participation Preferences

May we contact you about opportunities to participate in research studies?

You can choose how to be contacted in Notifications.

### Your Studies

Based on your medical record, you have been identified as potentially eligible for these studies. Click "I'm Interested" to notify the research team that you may want to participate in the study.

### Learning and Memory Study

Can learning and memory contribute to the persistence of the pain process?...[details](#)

Dear [Parent/Guardian of <Child's Name> ],

We are excited to tell you about a new research study. We are looking to partner with families who have children that are between 10 and 24 years.

### Participation Preferences

Your preferences will help us let you know about research opportunities that might interest you. Your care team might discuss additional opportunities with you.

### Related Links



Specify how you would like to receive MyChart notifications for research

# Response options (Direct Email or Epic MyChart)

1. “Yes, I’m interested” → participant contact preference passed on to study team for follow-up within 24-48 hours
2. “No, thank you” → recipient will no longer be contacted about **this** study
3. “Unsubscribe” → recipient will no longer be contacted via Research Participation for **any** study
4. No response → may be re-invited a max of 2 times, 2+ weeks apart (Direct Email only)

# Beyond Stanford: Stanford Research Registry

The goal of the Research Registry is to support Stanford research participant engagement, originally with a focus on COVID-19 studies, but designed for all types of studies.

Population: focused on **Bay Area beyond Stanford**, and open to everyone.

<http://goto.stanford.edu/StanfordRegistry>

Launched April 2020

As of June 2023: >10,800 registrants

**\*\*Now also available in Spanish\*\***



In 2020, the “COVID Long Haul Study” documenting persistent symptoms of COVID-19 infections recruited **>90 participants using the Registry**. In 2021, the Pfizer pediatric COVID vaccine trials recruited **>2,000 families using the Registry**.

# Beyond Stanford: Stanford StudyPages directory



<https://studypages.com/stanford>

Home **Studies**

Sex  Any  Male  Female

Age What's your age?

Types  Behavioral Studies (3)  Device Studies (1)  Drug Studies (3)  Other Studies (3)  Observational Studies (1) [Show all](#)


Topics  Coronavirus (COVID-19) (4)  Diabetes, Obesity, and Metabolism (1)  Ear, Nose, and Mouth (1)  Healthy Volunteer (2)  Kids, Infants, and Newborns (3) [Show all](#)


Departments and Centers  Infectious Diseases (2)  Neurosciences Institute (1)  Obstetrics and Gynecology [OB/GYN] (2)  Psychiatry and Behavioral Sciences (2)  Brain Tumor Center (0) [Show all](#)


Search studies   Sort by: Relevance ▾

12 Studies found

**Interested in these studies?**  
Find out when new studies you're interested in are available.

 **Study to evaluate Manganese and Mn-requiring enzyme activities in Chronic Fatigue Syndrome...**  
Manganese is an important trace metal for enzymes that are needed to metabolize glucose and amino acids. We are interested to learn if there are differences in these metabolic pathways between individuals with ME/CFS compared to healthy controls.  
Investigator: Ronald W Davis, PhD

 **Birth control study for women with endometriosis or uterine fibroids**  
*Explore an oral contraceptive study*  
This study aims to learn more about the safety and effectiveness of a study birth control pill to prevent pregnancy in women 18 to 50 years of age with uterine fibroids or endometriosis. The study medication is approved by the US Food and Drug Administration (FDA) to treat heavy menstrual bleeding.  
Investigator: Paul D. Blumenthal, MD, MPH, Professor of Obstetrics and Gynecology

 **Join our fertility study for Asian Men!**  
*Volunteer for fertility research and contribute to discoveries that may improve health care...*  
We're inviting men of Chinese, Japanese, Korean, and/or Taiwanese descent to join a fertility research study. The goal of this study is to see if there is a...  
Investigator: Michael Eisenberg



# Study Page



## 100% At-Home Clinical Study to Help Patients with Atrial Fibrillation Stay Protected on their Blood Thinner Medications

Stanford University



"We're looking for people that are currently taking a blood thinner for Atrial Fibrillation - receive a free wireless BP cuff & EKG machine!"

**Take survey to see if you qualify**



Investigator:



**Rajesh Dash MD PhD,**  
Director of SSATHI &  
CardioClick  
Stanford Medicine  
[View profile](#)

**Age:** 55 years and older

**Keywords:** Atrial Fibrillation, AFib, AF, Telehealth, At home study, remote study, home devices, heart rhythm study, Blood thinner, Anticoagulation

**Gender:** Any

**Type:** At-home clinical study

**Target:** 100 Participants

### Description

Are you taking a blood thinner medication for Afib (atrial fibrillation) or AFlutter (atrial flutter)?

Stanford University researchers are conducting a 100% at-home clinical study to help patients with atrial fibrillation stay protected on their blood thinner medications.

The goal of the study is to help you keep track of your blood thinner medication and help you learn more about your condition. Participate in this exciting new study without ever having to leave your home!

Using a study app plus a wireless home EKG sensor and blood pressure cuff, and regular app-based communications, we will help you understand your condition better and keep track of your blood thinner medication usage. You get to keep

### Schedule

**Study duration and period**

This study takes approximately 6 months

### Contact

**Jasmine LaCoursiere**

[jaslacou@stanford.edu](mailto:jaslacou@stanford.edu)

(650) 800-8023

# Pre-screen

\*1. Do you have a condition called atrial flutter, atrial fibrillation, or commonly 'Afib'?

\*2. Are you currently taking any one of the following oral anticoagulants?

Warfarin/coumadin, Rivaroxaban (Xarelto), Apixaban (Eliquis), Edoxaban (Savaysa), Dabigatran (Pradaxa), or other

\*3. Are you 55 years of age or older?

\*4. Do you have a smartphone (iPhone 6S, iPhone 7 or above, or Android version 6.0 or above)?

\*5. Have you ever received care (primary care or specialty care) at Stanford Health Care?



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# StudyPages Workspaces

for participant management and communication

The screenshot displays a user profile for [DA] Koen De Lombaert, including contact information and a 'Call' button. Below this are sections for 'Enrollment Status' (set to 'Contacting') and 'Last Message'. A 'Log' section shows a history of phone calls. The 'Visits' section contains a table of scheduled study visits. On the right, a 'Text Messaging' window shows a conversation with Eron Villarreal, including an incoming message 'Hi Koen!' and an outgoing message 'When is a good time to chat?'. A text input field at the bottom of the messaging window is labeled 'Enter your message here'. Green callout boxes highlight 'VoIP', 'Pre-screening log', 'Visit Scheduling (in-person / Video)', and 'SMS chat'.

[DA] Koen De Lombaert  
koendelombaert+1@gmail.com  
(443) 799-7409 [Call](#)

[Edit](#)

**Enrollment Status**  
Contacting

**Last Message**  
a ye

**Log** [Add Note](#) [Mark unread](#)

- Phone call was made 4 months ago
- "I called and left a VM" 8 months ago

**Visits** [Schedule Study Visit](#)

Visit Name	Scheduled Date	Status
Screening	2020-07-22, 12:00 PM	Pending - Date Passed
Baseline	2020-07-02, 05:30 PM	Pending - Date Passed
Follow-Up	2020-07-21, 04:00 AM	Pending - Date Passed

**Text Messaging**

Eron Villarreal - Sep. 18, 2019 at 3:53 pm  
Hi Koen!

[DA] Koen De Lombaert - Sep. 18, 2019 at 3:53 pm  
When is a good time to chat?

Enter your message here



# Community Outreach & Engagement

- Connect with our Community Engagement colleagues for recommendations on building community partnerships
  - Is this for simply advertising a study or working more in partnership?
  - “Best to build a partnership when you’re not asking for something”

Request Technical Assistance



<https://app.smartsheet.com/b/form/7d48678c125c418fbecd9ca2b61b2995>

- The Stanford Community Advisory Board (CAB) aims to:
  - enable community members to participate in research planning and dissemination of findings.
  - provide feedback to researchers on recruitment strategies, including reaching specific populations.

Contacts:

[communityengagement@stanford.edu](mailto:communityengagement@stanford.edu) (adult)

[dongmei@stanford.edu](mailto:dongmei@stanford.edu) (maternal child)



# Engaging Underrepresented Minorities (URMs)

Barriers to participation among racial/ethnic minorities

Potential solutions to overcome barrier

## Logistical

Lack of awareness of clinical trials

- Recruit in community locations in partnership with local agencies
- Patient navigators can increase awareness of clinical trials
- Providers and staff can ensure that racial/ethnic minority patients are aware of clinical trial participation options

Costs associated with participation in trials

- Plan for adequate compensation to overcome logistical barriers
- Communicate research related costs early and clearly

## Psychosocial

Lack of trust in the Stanford healthcare system, and medical research in general

- Publicly acknowledge and apologize for past wrong doings
- Patient navigators can increase trust
- Diverse healthcare delivery staff
- Extremely clear consenting process is important
- Cultural competency training related to racial/ethnic minority participation in clinical trials

# Engaging Underrepresented Minorities (URMs)

Barriers to participation among racial/ethnic minorities	Potential solutions to overcome barrier
<b>Psychosocial (cont'd)</b>	
Fear of risks/adverse effects associated with being in a trial	- Extremely clear communication and consenting process is important
<b>Structural</b>	
Language barriers (study materials, study staff, etc.)	- Ensure accessibility related to language for all study materials and activities - Provide better access to, and expansion, of hospital interpreter services
Exclusion criteria that disproportionately limit eligibility among racial/ethnic minority patients	- Examine exclusion criteria with a disparities lens to identify criterion that may limit racial/ethnic minority participation

*Adapted from Stanford's Office of Community Engagement*

# Trial Innovation Network (TIN)

A national network within the CTSA Program that provides support for multi-site clinical research

Multi-site = 3 or more sites

- Expert methodological and logistical guidance
- Competitive funding advantage
- Access to the entire CTSA network



# Trial Innovation Network (TIN)

TIN offers investigators consultations and resources for multi-center clinical research including:

- Protocol development
- Community engagement studios
- Recruitment planning
- Feasibility assessment
- Recruitment materials
- EHR-based tools & resources
- Trial budgeting guidance



393 Total Proposals Submitted

76 Therapeutic Areas Represented



61 CTSA's Submitted Proposals

20 NIH Institutes and Centers Engaged

NIAID	NIAMS	NIBIB
NIHCD	NIDCD	NIDCR
NIDDK	NIDA	NIEHS
NIGMS	NIMH	NIMHD
NINDS	NINR	NLM
NCI	NCM	NCRR

# Trial Innovation Network (TIN)

## Two ways to get involved in the TIN:

1. The local TIN Liaison Team will connect investigators with multi-site clinical trials initiated by other network sites
2. Stanford investigators may submit proposals for multi-site trials to the TIN



## Contact:

Stanford TIN Liaison:

Maya Berdichesky, [mayab2@stanford.edu](mailto:mayab2@stanford.edu)

## To learn more:

<https://med.stanford.edu/spectrum/researcher-resources/trial-innovation-network.html>

<https://trialinnovationnetwork.org>

# Research Participant Engagement Program Expands

- In response to increased demand from study teams and to better serve the greater Stanford research community
- To increase opportunities to participate in research for people of all backgrounds
- Our model includes one-hour free consultations and an array of services for study teams, including Direct Email, Epic MyChart, Postal Mail, and Stanford Research Registry outreach.
- Visit our website for Standard and Add-On Services and their associated costs, as well as for Participant Engagement Tips and Resources and a “How to Plan a Recruitment Budget” template.



# How to Plan a Participant Recruitment Budget

- Staff effort and costs associated with participant recruitment almost always **underestimated**
- Incorporating sufficient funding into grant proposal budget is essential for attaining enrollment goals
- If you haven't already, brainstorm using our [Recruitment Strategizing Worksheet](#) to get started.

For planning your budget, consider:

- **Study population:** Is the pool of eligible participants large or limited? Stanford patients or beyond Stanford?
  - For large participant populations, consider broad approaches, such as social media, newspaper ads, and posting flyers in high visibility areas. Our Stanford Research Registry or Direct Email “honest broker” outreach may also be a good fit.
  - For highly specific participant populations, consider budgeting for more staff time to conduct chart reviews, clinic recruitment, and outreach to relevant patient advocacy/support groups. Our Epic MyChart “honest broker” outreach may also be a good fit.

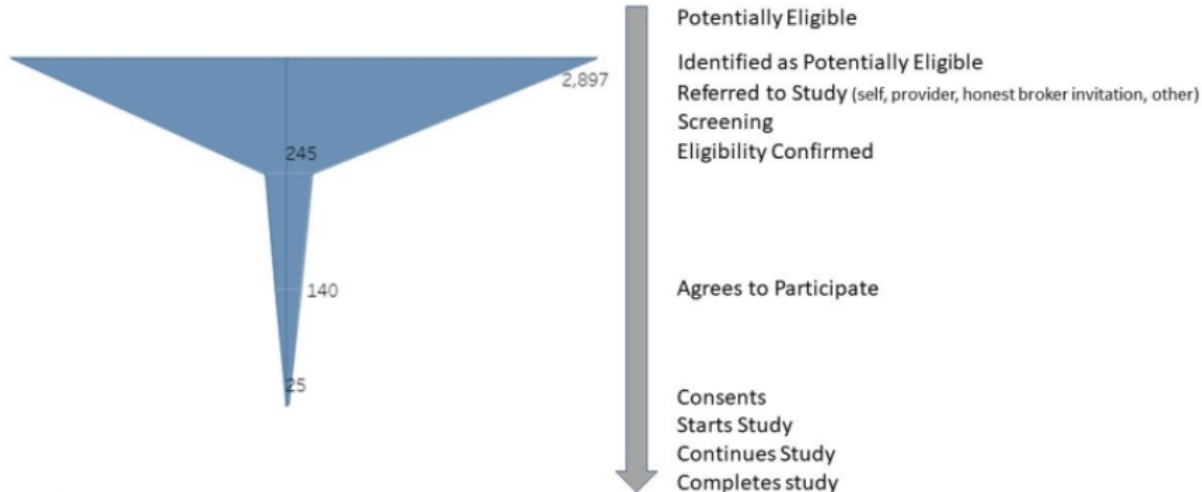




# How to Plan a Participant Recruitment Budget (cont'd)

- **Estimated Eligible Rate:** How many people will you have to screen to identify eligible participants?
  - Recruitment is always harder than anticipated. If you estimate a 6:1 screening to enroll rate, budget for 10:1. Consider the “Recruitment Funnel” below. For example, if your enrollment goal is 100 participants, how will you engage 1,000 potentially eligible participants?

## Recruitment Funnel



*Real data for a Stanford study using PEP "honest broker" Direct Email*

# Participant Engagement Budget Planning Template

Recruitment Method	Unit Cost (e.g. per print, week, letter)	Number	Effort (hours)	Total Cost	Notes
<b>Stanford patients</b>					
PI invites own patients					At patient visits? Individual MyHealth messages? Letters? Phone Calls?
PI-Provider co-invitations					Using STARR Chart Review and/or PI network?
PEP "honest broker" Direct Email or Epic MyChart (up to 6 waves)	\$704- \$1,799	1		\$704- \$1,799	
PEP "honest broker" Postal Mail (1 wave)	\$454- \$908	1		\$454- \$908	
Flyers/brochures/postcards for clinic waiting rooms (\$/print)					Obtain clinic leadership endorsement and document this in your IRB protocol
<b>Beyond Stanford</b>					
Stanford Research Registry (up to 2 waves)	\$386- \$772	1		\$386- \$772	Ideal for healthy volunteers and common conditions
Social Media ads (\$/week)	\$50	24		\$1,200	Consider Facebook, Instagram, Twitter, others
Flyers (\$/print)	\$0.64	200		\$128	
Reach out to local patient support/advocacy groups					
Craigslist/Nextdoor study listing					Nextdoor could be free or paid...

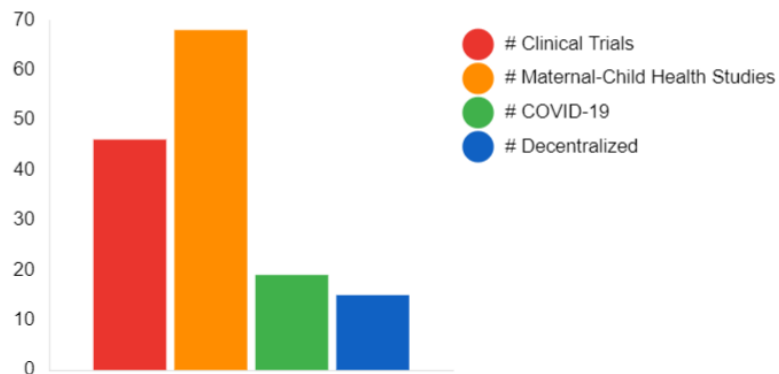
# Participant Engagement consults



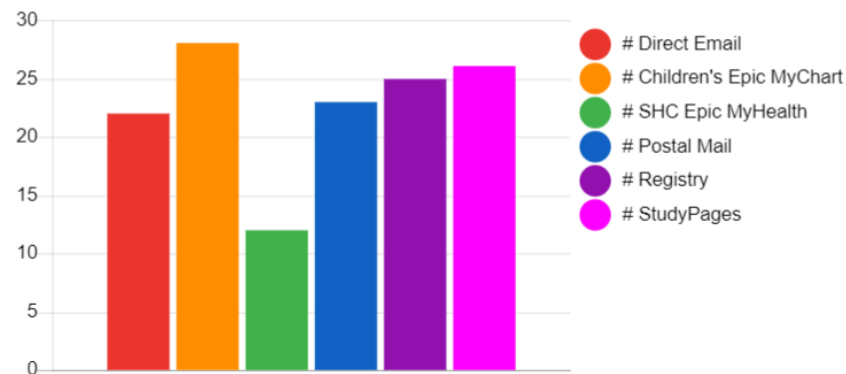
**185**  
**Total Initial Consults**  
**Aug 2019 - June 2023**

*(SHC MyHealth launched Sept 2022)*

**Study Type Distributions**



**RPP Service Type Distributions**



# PEP, BPAs, Research Registry, and StudyPages Per Channel Totals

As of May 2023

	# Studies	# Invitations	# Interested	% Interested	% Interested Range	Date Launched
Direct Email	12	92,824	1,578	1.7%	0.1 - 7.7%	Feb 2020
Children's Epic MyChart	26	43,741	1,487	3.4%	0.6 - 21.4%	Mar 2020
Postal Mail	17	7,005	154	2.2%	1.0 - 31.6%	May 2020
SHC Epic MyHealth	8	12,475	337	2.7%	1.1 - 10.3%	Sep 2022
<b>PEP Total (unique studies)</b>	<b>46</b>	<b>156,045</b>	<b>3,556</b>	<b>2.3%</b>		
<b>Children's Epic BPAs</b>	<b>3</b>	<b>5,805</b>	<b>1,444</b>	<b>24.9%</b>	<b>22.8 - 38.5%</b>	May 2020
<b>Stanford Research Registry</b>	<b>27</b>	<b>21,275</b>	<b>3,270</b>	<b>15.4%</b>	<b>0.2 - 66.7%</b>	April 2020
SRR- not COVID related	22	14,311	1,107	7.7%		
SRR- COVID related	5	6,964	2,163	31.1%		
<b>StudyPages</b>	<b>89</b>	<b>Views/Clicks:</b>	<b>Sign-ups:</b>	<b>Of Views:</b>		Jan 2018
		<b>274,587/16,025</b>	<b>13,127</b>	<b>4.8%</b>		

Thank you. Questions?  
[EngageParticipants@stanford.edu](mailto:EngageParticipants@stanford.edu)  
Research Participant Engagement Program



Sijo Thomas (Children's Clinical Research Informatics) & Katherine Connors



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