



# Research for Me

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Purpose, Process, and FAQ

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# OVERVIEW

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- Introduction and background
- Listing Requirement
- Process to submit your listing
- Study listing choices
- Managing your listings
- Questions and feedback

# RESEARCH FOR ME @UNC

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Listing process launched in Nov 2019, Public site launched in Feb 2020



Comprehensive, searchable study listing; optional recruitment tool



Public-facing research engagement website with over 11,000 registered users



Learn about research, view current research, find relevant participation opportunities, read stories and profiles highlighting study teams and participants



Created by the Recruitment and Retention Program at the NC TraCS Institute



To address existing gap between incredible work happening at UNC and ability of patients/public to learn about what we do and access opportunities to engage with research

# THE VISION

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Create a UNC-branded “front door” for any patient or member of the public wishing to engage in research here



Improve transparency, accessibility, and familiarity



Lay-language



Provide a way to engage at any level



Provide a way for researchers to find collaborators and assess saturation



Promotion and visibility in all UNC clinics and publicly across the state. Already accessible via MyChart and soon from the UNC Health Research page

# PLANS FOR THE FUTURE

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Partnership with UNC and UNC Health

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Explore possibilities for use by patient navigators/physicians

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Departmental widget

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Study metrics, improved clarity, and resources on RD

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Study customization options

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Condition search dictionary

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Enhanced user profile and personalization options with tailored content

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Newsletters and suggested study emails

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PR campaigns and social media presence

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Option to use RFM avenues to promote individual study opportunities

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# BENEFITS

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- ✓ Streamlined, united front presented to the public
- ✓ Automated, up to date information
- ✓ Unique landing page for every study
- ✓ Individuals more aware of research
- ✓ Individuals more receptive and willing to engage
- ✓ Improve “customer service”
- ✓ Expand reach and diversity
- ✓ Improve synergy and transparency

# LISTING REQUIREMENT

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- Applies to Human Subjects Research involving direct interaction with subjects
- Listing is required; use as a recruitment tool is not
- There are special circumstances where it is appropriate to request to opt out of the listing requirement
- Listing is done once per study, but can be edited later if desired/needed

# Resources

Listing Mechanism	REDCap form accessed via question B.1.2 in IRB app	Required for all HSR involving direct interaction with participants Choose Basic or Recruitment listing
Listing Management	Researcher Dashboard ( <a href="https://researcherdashboard.unc.edu">researcherdashboard.unc.edu</a> )	IRB-approved personnel can access REDCap forms to manage information
Public Engagement	Research for Me @UNC ( <a href="https://researchforme.unc.edu">researchforme.unc.edu</a> )	Search for relevant studies, read stories, learn about research participation



# SUBMITTING YOUR RESEARCH FOR ME @UNC STUDY LISTING

# THE PROCESS

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- Prompt within IRB application with link to unique REDCap form.
- For existing studies: at the time of your next IRB modification or renewal
- For new studies: at the time of your initial IRB application
- Use succinct, plain language to describe your study, do not copy and paste from protocol

# INSTRUCTIONS – B.1.2

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## Research for Me @UNC

This public engagement website is intended to improve the transparency and accessibility of research conducted by UNC or UNC-affiliated researchers. It features a comprehensive list of active studies involving direct interaction with participants. All studies must be listed - make a selection below and submit your listing information via the link. [View examples](#)

### Instructions:

- Choose Basic or Recruitment
- Click on link to open listing submission form in a new tab
- Submit online form, download PDF
- Receive submission confirmation email (PDF also attached)

Special Circumstances: on rare occasions, a study may request that a listing not be published. The acceptable reasons for that request are included as options below. If you feel that you meet criteria for an option other than Basic listing or Recruitment listing, please select that option. Note that upon review, your selection must match information in the rest of your application.

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# YOUR CHOICES

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**Basic Listing** ([Click here to open basic submission form](#))

For studies which are recruiting by invitation only, physician referral only, or don't want to be contacted by potential participants. Submit very basic information in lay language. Improves public transparency of the studies being done at UNC, but no team contact information will be displayed.

**Recruitment Listing** ([Click here to open recruitment submission form](#))

For studies who want to use the listing a free recruitment tool. Submit both basic and recruitment information so that potential participants can express interest in your study. You control the time frame when study team contact information is visible for recruitment purposes. Site will be promoted to patients and the public. Your listing can be used as a landing page from other recruitment materials to provide more details.

- Opt-Out:** This study is classified, and even basic information is prohibited from public display
- Opt-Out:** This study involves deception, and would be compromised by public listing
- Opt-Out:** This study is of such a specific and sensitive nature that public listing would compromise participant confidentiality
- Opt-Out:** Enrollment of new participants is complete OR UNC is acting only as the Data Coordinating Center and will not be enrolling participants

View examples, manage submitted listings, find FAQ, and download PDFs at [researcherdashboard.unc.edu](https://researcherdashboard.unc.edu)

Please direct all questions and feedback to [Research for Me](#)

# TYPES OF STUDY LISTING

## Basic

- Required
- Displays limited information about the study
- Members of the public unable to express interest; no study team contact information displayed
- Shorter submission form

## Recruitment

- Optional
- Include extended information about study participation
- Potential participants can contact study team to express interest
- Unique URL – used as landing page for recruitment materials or social media
- Free

# BASIC LISTING

- Basic-only listings are appropriate for studies who do not wish to be directly contacted by interested potential participants. Providing this basic information on a public-facing site improves transparency of our work, trust in our product, and curiosity about the research process.
- You will be asked to select a reason for choosing the basic listing: by physician referral only or by invitation only

Item	Entry
IRB number	Generated from IRB app*
Study Nickname	Manual entry
Short Study Title	Manual entry
Study Purpose	Manual entry
Primary condition	Manual entry
Study topics	Select all that apply
Participant Gender	Select all that apply
Gender Identity	Select all that apply
Participant age range	Manual Entry
Language	Select all that apply
Location	Select appropriate
Study type/design	Select one
Listed on CT.gov?	Generated from IRB app*
CT.gov number	Manual entry
PI information	Generated from IRB app*
Existing team or study URL (optional)	Manual entry
Select a reason for basic only	Select one
Housekeeping items	Confirm

# NOTES ABOUT THE BASIC LISTING

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- This form should take 5-10 minutes and only needs to be completed once. Listings will remain visible until the IRB is notified that enrollment is complete
- Short study title and study purpose are purposefully not populated from the IRB application – please be thoughtful in how you write these
- IRB will check to be sure the REDCap form was completed
- IRB will not review the information in the form – you do not need to upload the PDF as an attachment

By physician referral or invitation only

## Blood Pressure Medication Study

The purpose of this study is to find out if a simple blood test could help your doctor decide the best kind of medication for you and your body.

### Age & Gender

30 years – 60 years

Male, Female, Gender Inclusive

### Contact the Team

Thank you for your interest, but this study is recruiting by invitation only.

### Location

North Carolina - Orange

### Additional Study Information

#### Principal Investigator

Sam Smith  
NC TrACS

#### Study Type

Clinical or Medical  
Interventional

#### Study Topics

Heart and Circulation

IRB Number  
XX-XXXX

ClinicalTrials.gov  
NCTXXXXXXX



# RECRUITMENT LISTING

- Utilize your listing as a free recruitment tool, allowing potential participants to express interest by contacting the study team directly.
- A recruitment listing contains all of the basic listing information, plus additional information intended to recruit participants
- For a recruitment listing:
  - Basic information will display from the time of IRB approval to the time that enrollment is marked at complete in IRBIS
  - Recruitment information will additionally display during the time frame you select.

Item	Entry
Recruitment Window Start	Manual entry
Recruitment Window End	Manual entry
Recruitment Pitch	Manual entry
Healthy Volunteers? (HV)	Manual entry
Inclusion / Exclusion for HV	Manual entry
Recruiting specific condition? (SC)	Manual entry
Inclusion / Exclusion for SC	Manual entry
# of in-person visits	Manual entry
# of remote visits	Manual entry
What will you ask of the participant?	Manual entry
Total length of participation	Manual entry
Available hours for visits	Manual entry
Compensation and incentives	Manual entry
Screening survey	Manual entry
How many locations	Manual entry
Contact information	Manual entry
Location information	Manual entry
Housekeeping items	Confirm

# NOTES ABOUT THE RECRUITMENT LISTING

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- The additional time it takes to complete this information will vary depending on the team and the study
- It only needs to be completed once. Recruitment listing information can always be managed and edited via the Researcher Dashboard
- Use checkbox at the end of the form to request optimization of your recruitment language before you upload the PDF. We want your listing to be the best it can – fresh eyes and recruitment expertise can be useful.
- PDF of this listing type needs to be attached to IRB application for review, just as with any recruitment material

# NOTES ABOUT THE RECRUITMENT LISTING

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- Extended recruitment information is intended to help someone decide if they might be interested and eligible – the goal here is simply to provide enough information to interest them and help them decide whether to contact you.
- 8<sup>th</sup> grade level. We know it may be tempting to copy information from protocol/consent, but spending a little extra time to provide clarity in the listing form could help make your listing more enticing to potential participants.
- Study purpose vs. Recruitment pitch
  - Both should be about your study; Recruitment pitch is to convince people to click to read more about your study.
- Only 5 each for inclusion/exclusion criteria
  - No need to include age/sex/gender
  - If you have more than 5, pick the 5 most important – don't want people to disqualify themselves if they don't understand or aren't sure they fit.

Not currently available

## Blood Pressure Medication Study

The purpose of this study is to find out if a simple blood test could help your doctor decide the best kind of medication for you and your body.

I'm interested

### Age & Gender

30 years - 60 years  
Male, Female, Gender Inclusive

### Incentives

Compensation  
Study medication, procedure, or  
treatment at no cost

### Location

North Carolina - Orange



#### What will be asked of you :

If you choose to participate, you will visit the Clinical & Translational Research Center 4 times. During each visit, we will draw a small amount of blood, ask that you take an FDA-approved medication every day, and answer some questions about how you are feeling.



#### Incentive :

up to \$250, Study medication

In-person visits : 4

Total length of participation : 8 months

### Looking for Specific Volunteers

#### Able to participate :

- You have high blood pressure

#### Not eligible if :

- You are taking a blood pressure medication
- You have diabetes

### Contact the Team

#### Primary Contact

Sam Smith  
research\_for\_me@unc.edu

### Location

#### Primary Location

Clinical & Translational Research Center  
180, Burnett-Womack Building, Dental Ctr,  
Chapel Hill, NC 27514, USA



### Additional Study Information

Principal Investigator  
Sam Smith  
NC TRACS

Study Type  
Clinical or Medical  
Interventional

Study Topics  
Heart and Circulation

IRB Number  
XX-XXXX

ClinicalTrials.gov  
NCTXXXXXX

# SPECIAL CIRCUMSTANCES – OPT OUT

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Classified Research



Research Involving  
Deception



Research of such a specific  
nature that public listing  
could harm participants



Enrollment complete

# WANT TO PREPARE AHEAD OF TIME?

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- Familiarize yourself with the REDCap listing form

- **Basic:**

[https://redcap.researcherdashboard.unc.edu/surveys/?s=3498D3L9YL&rc=JNFDM9CR&\\_\\_return=1](https://redcap.researcherdashboard.unc.edu/surveys/?s=3498D3L9YL&rc=JNFDM9CR&__return=1)

- **Recruitment:**

[https://redcap.researcherdashboard.unc.edu/surveys/?s=3498D3L9YL&rc=WP8AAHWH&\\_\\_return=1](https://redcap.researcherdashboard.unc.edu/surveys/?s=3498D3L9YL&rc=WP8AAHWH&__return=1)

*\*Please **do not submit any real information via these links** – they are meant solely for educational purposes to become familiar with the form prior to actual submission. Do not enter your actual ONYEN, Health ID, or email.*

- View examples for a mock study. See completed PDFs and how that information is displayed live on the site
  - <https://researcherdashboard.unc.edu/index.php/examples>
- Decide which kind of listing will be most appropriate for your study, use the tables on the RD Examples page to gather the needed information, and compose draft answers to quickly fill in the online form at the time of submission.

# MANAGING YOUR RESEARCH FOR ME @UNC STUDY LISTINGS

# RESEARCHER DASHBOARD

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- Log in with ONYEN or Epic ID
- View all listings on which you are IRB approved personnel
- Sorted into Pending, Active, and Inactive studies
- Edit listing information
- Edit recruitment window or “pause” visibility
- View unique URL, generate QR code, get an updated PDF
- FAQs and Lay Language resources








HI JINHEE PAE,

Here, you can view and manage all Research for Me @UNC study listings for which you are IRBIS listed personnel. To learn more about listing options, see [detailed guidance](#), and [view FAQ](#).

Please remember that certain changes may need to be done in conjunction with an IRB modification and that the team is responsible for ensuring the accuracy of the listing in accordance with IRB-approved materials.

## Active Studies





Currently visible on the Research for Me

IRB #	STUDY TITLE	LISTING EXPIRING ON	EDIT	DOWNLOAD	RESEARCH FOR ME
19-2852	Performance and recovery effects of pre- and post-workout supplementation with high intensity resist...	November 17, 2020		 	<b>STUDIES.UNC.EDU/19-2852</b>  

Showing 1 to 1 of 1 entries Previous  Next Show 10 entries

## Pending Studies

Listings associated with an IRB submission that has not yet been approved

IRB #	STUDY TITLE	LISTING EXPIRING ON	EDIT	DOWNLOAD	RESEARCH FOR ME
19-3450	Recruitment Testing Study...	March 7, 2020		 	<b>STUDIES.UNC.EDU/19-3450</b> 

Showing 1 to 1 of 1 entries Previous  Next Show 10 entries

## Inactive Studies

Not visible on the Research for Me

IRB application indicates that enrollment is complete or study is in data analysis only. Listings may also be inactive if the IRB application is expired, closed, withdrawn, or disapproved.

IRB #	STUDY TITLE	LISTING EXPIRED	EDIT	DOWNLOAD
11-0477	TrialNet Pathway to Prevention...	November 14, 2018		 

Showing 1 to 1 of 1 entries Previous  Next Show 10 entries

# COMMON QUESTIONS

# WHY CAN'T YOU PULL ALL OF THE BASIC LISTING INFORMATION FROM MY IRB APPLICATION?

- Very different audiences
- For the free text field, the IRB application typically includes way more information than is appropriate to display to the public
- Much of the information relevant to the public is not captured in discrete fields within the application
- We pull what we can and will look into further integration with other systems where study information is already captured

# WILL THE IRB BE ISSUING STIPULATIONS ABOUT THIS?

- Basic Listings
  - IRB analysts will confirm that a REDCap listing form has been completed and submitted. No stipulations will be issued for content
- Recruitment Listings
  - IRB analysts will review the required RFM PDF attachment, just as with any other recruitment material
  - Stipulations may be issued for content or language. Changes should be made via Researcher Dashboard and an updated PDF uploaded to the application
- Opt-Out requests
  - RFM administrators and IRB analysts will consider whether the request matches information indicated throughout the rest of the application. The application will not be delayed for this, but teams will be asked to correct the option if not appropriate.

# CAN I CHANGE MY MIND LATER ABOUT THE LISTING TYPE?

- Basic to Recruitment
  - Must be initiated during an IRB modification
  - Team will change listing choice and click on link to complete the additional listing information
  - PDF should then be attached for IRB review
    - Extended information will go live based on approval and on your indicated recruitment window
- Recruitment to Basic
  - Can be done anytime via Researcher Dashboard
  - Simply change your “recruitment end date” and save

# DO I NEED TO RESUBMIT TO THE IRB IF I CHANGE THE LANGUAGE IN MY RECRUITMENT LISTING?

- The information in a recruitment listing is treated just like any other recruitment material
- Please be sure that any changes you make are consistent with changes already approved by the IRB
- Changes to the nature of the recruitment language or facts of the study can be done and uploaded with the modification indicating those changes to the IRB

# HOW DO I COMPLETE A RECRUITMENT LISTING FOR A RELY-ON STUDY?

- Information displays on the public site based on UNC IRB approval status
- Always check with the specific office, but studies relying on an external IRB may choose to:
  - Complete the REDCap form and submit, indicating a “recruitment start date” in the future
    - Submit the PDF for approval as recruitment material and update the start date via Researcher Dashboard once approved
  - Use already approved language from the consent form
  - Select basic listing to start and update to recruitment listing later
    - Draft the listing information in a word document and submit to external IRB for approval
    - Submit UNC modification to change the listing type and use approved information for the REDCap form

# HOW WILL I BE NOTIFIED WHEN SOMEONE IS INTERESTED IN MY STUDY?

- A potential participant can express interest in a few different ways:
  - “I’m Interested” button – for registered users
    - Sends study contact an email (default)
    - Directs person to your IRB approved screener
    - Directs person to your IRB approved online consent
  - Direct team contact information – for non-registered users
    - Phone or email



# CAN I DIRECTLY REACH OUT TO REGISTERED USERS TO RECRUIT THEM?

- Site is completely user driven
- Users will be able to sign up to be notified when new studies matching their interests are listed
- Study teams can use their study-specific page as a landing page for participants targeted via other recruitment efforts
- In the future, the departmental widget will allow teams to generate a live feed of their own studies to embed on their own websites, if desired.

# HOW DO I REMOVE MY STUDY OR STOP USING IT FOR RECRUITMENT?

- To stop display of the recruitment information, simply log into Researcher Dashboard, select the appropriate study, and edit the “recruitment end date”
- Our system refreshes information nightly
- Basic information will be removed from the site when you indicate to the IRB that enrollment has closed, that the study is in data analysis only, or when the application itself has been closed with the IRB

# I HAVE SPECIFIC QUESTIONS ABOUT MY STUDY OR SITUATION RELATED TO RESEARCH FOR ME @UNC. WHO CAN I CONTACT?

- We want to limit burden and make this optimally useful for everyone. We welcome questions and feedback. We'll be continuing to refine the process and features moving forward.
  - [Research\\_for\\_me@unc.edu](mailto:Research_for_me@unc.edu)
- I am happy to provide trainings or listening sessions for individual groups and talk through various situations and processes.
  - [emolsson@unc.edu](mailto:emolsson@unc.edu)



Thank you!

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