Respectful First Contact:

Best Practices for Initial Communication with Potential Research Participants

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What We Will Cover

Best practices throughout the recruitment process:

- Before Contact:
  - Importance of preparation and eligibility verification prior to contact
- During Contact:
  - Mode of communication and professional practices
  - Recommendations for participant interactions and confidentiality considerations
- After Contact:
  - How to handle participant complaints
  - When/how to escalate to the IRB

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Recruiting Participants
Not Part of "Your" Patient Population

- It can be tricky to communicate with individuals you have no relationship with
- These patients are unknown to you and not part of your clinic population
- You are not known to them, part of their healthcare team, and can be perceived as an *invasion of their health privacy*
- It is important recruitment be done in a *thought out* and *respectful* manner and in consideration of *best practices*

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Best Practice #1 - Put yourself in their shoes

- How would you feel if someone you did not know and did not receive care from received your personal information?
- And then contacted you about research based on their access to that personal information?
- It can be a startling and worrisome situation when an unknown person is contacting you with your PHI
- Start recruitment by thinking from their point of view and develop, create and communicate from this place
  - If enrolling vulnerable populations or focusing on sensitive topics, extra consideration is needed

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#2 – Confirm eligibility before contacting

- Build a good potential participant query
  - Use inclusion and exclusion criteria
  - Include criteria not explicitly stated
    - Exclude deceased patients
    - Epic flags of concern (*more at upcoming research forum*)
    - Exclude patients who haven't been seen in years
    - Include patients who had an actual OHSU provider encounter

- Confirm! Confirm! Confirm!
  - Once you receive the dataset, perform a chart review and prescreen the patients to ensure they meet eligibility
  - Perform an additional check for any criteria that could have other explanations (e.g. BMI = pregnancy)
  - Only contact those you have confirmed eligibility

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#3 – Mode of communication

- Select the best mode of communication for your study
  - Phone call, Email, Letter, MyChart Message
  - Consider the topic and the sensitivity and privacy needed

- Cold calling not recommended
  - Consider sending a letter/email about your study prior to calling them

Remember, always consider the target population and how they best receive information

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Recommended Phone Communication Content

1. Ensure you are speaking with the intended individual.

2. Start with introductions – you are a stranger to them!
   Be sure to state:
   - Who you are
   - That you are with OHSU
   - What you do
   - Why you are reaching out to them

'Hello, my name is Jane, am I speaking with John? Hi, John, I am a research coordinator with the Department of Neurology from Oregon Health & Science University. We have a research study that you may be eligible for and interested in. Is this a good time to talk?'

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3. Don't leave voicemails with study specific or health information.
    - You can include your name, OHSU phone number, and a request for them to call back.

'Hello, my name is Jane from OHSU, and I am calling for John. Please call me back at your earliest convenience. I can be reached at 503-494-8927.'

Please see the [Telephone Recruitment and Screening Script Template]() on the IRB Policies and Forms page.

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Recommended Written Communication Content

1. Start by informing them who the investigator is and their connection to OHSU.
    - Mention any collaborations or affiliate site approvals.

2. After introducing the PI, make it clear that this communication is about research.

3. Next, state why you are reaching out to them (potential eligibility) and what participating entails.
    - Include compensation details and any other pertinent information to help them make an informed decision.

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4. Your last paragraph should state the next step or action item.
    - Make it clear to them what happens next and what they should do
    - For example, click a link, call the study team, the study team will call them, etc.

5. End of communication should include the name of study, OHSU IRB number and study team's contact information.
    - Always include your contact information no matter the mode!

Example of Recruitment Letter/Email

*Taken from OCTRI Recruitment's *"Recruiting Participants Not Part of your Patient Population"* [guidance document]

Subject Line: OHSU Research Opportunity: <Brief tagline re: your study>

Dear <Name>,

Dr. <Name>, a physician at OHSU specializing in <specialty>, is leading a study on <study disease/condition topic>, <if applicable> in collaboration with <provider and/or healthcare organization name(s)>. The goal of this study is to <state purpose of study in plain, 6th grade reading level language that is understandable to the general public>.

You are being contacted because <state why you believe they are eligible (e.g. "were seen in the emergency department in the last month")>. Participation in this study includes <state a brief summary of what their participation includes, what you are asking of them, including estimated time commitment and location of study visit(s) if applicable>. Participation in this study is voluntary. If you participate in this study, you will receive <compensation details> to compensate you for your time and efforts.

Final paragraph based on recruitment approach:

- <Team to call> We will be calling you to further discuss this study and if you are interested in participating. If you do not want us to call you, or are not interested in participating, you may contact us at <contact information> and we will not contact you further about this study.
- <Patient to call> To learn more about this study or find out if you are eligible, please visit <hyperlink>. For questions, or to speak to the study team, please call <phone number>.
- <MyChart> If you are interested in this study, please click the Clinical Research Opportunity link above to respond to the study team.

Thank you. We appreciate your consideration of our research study.

Sincerely,

<Investigator Name>

<Name of Study>

<OHSU IRB #>

<Contact phone and/or email for study team>

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#4 – Health literacy

- Write at a 6th grade reading level
- Keep sentences short & format for readability
- Define medical terms simply (e.g., "make worse" vs “exacerbate”)
- Use active voice and “you”
- Test with people not involved in research for comprehension
- Translate to participant’s preferred language & communication style
- Consider age, cognitive ability, and visual level and adapt as needed

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#5 – Create an FAQ

- There will be questions about the process and study that potential participants, or even your study team, may have.
- Create an FAQ of the top questions/concerns you expect to receive for internal use.
- Continually update this document as recruitment progresses and new questions/concerns are identified.
- Examples include:
  - How did you obtain my information and what information have you seen?
  - I want to speak to someone in charge about being contacted about research

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Knowledge Check In

Let's test our knowledge on reaching out to patients we don't know

Scenario #1 – A weight loss study sent letters out to individuals with a BMI above a certain number. A complaint was received because one of those individuals was pregnant. What could have been done better?

a. They should have chosen a different mode of communication
b. Team should have reviewed medical chart for accuracy prior to contact
c. Nothing, this was perfectly handled

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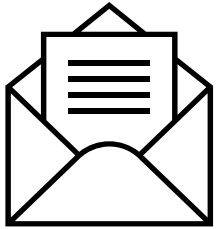
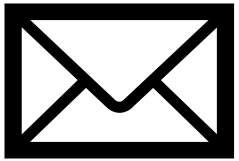
Scenario #2 – Your team calls and receives the potential participant's voicemail. What type of information should not be left in the voicemail?

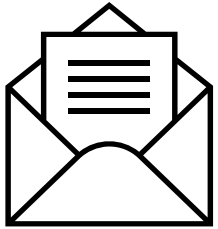
a. Their diagnosis or qualifying event
b. The topic/disease the study is researching
c. The name of the research study
d. All of the above

Scenario #3 – Your team is mailing out recruitment letters, for patient privacy, what type of envelope is best used?

a. One with your department specific information/return address area
b. One with study specific information/return address area
c. One with standard OHSU information/return address area







Handling Complaints

- *Patient* complaint or *Provider* complaint?
- Listen actively without defensiveness
- Show empathy and take concerns seriously
- Thank them for feedback
- Maintain professionalism – focus on patient satisfaction
- If this was MyChart recruitment, you can walk the patient through the option to opt out of MyChart Recruitment

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Can Patients Opt Out of Research Contact?

- There is no way for patients to opt out of all research/research contact at OHSU
- Patients can opt out of My Chart recruitment messages
- Participants can always decline research participation at the point of contact

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Escalating Complaints

- If an individual is not satisfied with the responses provided by the study team and is looking to talk to someone:
- Step 1: Provide the individual with the contact information for the integrity helpline – ohsu.edu/helpline, or (877)733-8313
- Step 2: Study team should contact the integrity helpline (as soon as possible) and provide the following information:
  - Name of study, name of individual, their complaint/request as you understand it, circumstances (e.g. affiliate patient, sensitive study topic, didn't meet inclusion/exclusion criteria)
- Submit a Reportable New Information (RNI) submission to the IRB if the complaint meets the RNI criteria (See RNI Quick Guide)

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Upcoming OCTRI Research Forum

- Finding a Mentor That Fits: Purpose, Boundaries, and Relationship Evolution
  - Presenter: Brenda Campbell
  - March 12, 2026, 2:00-3:00
  - Audience: Early Career Investigators
- Best Practices: Electronic Health Record (HER) Tool Selection and Query Development for Study Recruitment
  - Presenters: Jiro Inoue, Manager OCTRI Research Datawarehouse and Lindsey Zimmerman, OHSU Data Concierge
  - June 2, 2026, 12:00-1:00
  - Audience: Investigators, Research Staff

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Thank You