

Carolina Data Warehouse for Health (CDW-H)
Suggested Language to use in Recruitment Letters, Emails and Telephone Scripts

The examples below include suggested language for Investigators to use when contacting potential research participants whose names were obtained from the Carolina Data Warehouse for Health (CDW-H). Please note that any recruitment letters, emails or telephone scripts must be reviewed and approved by the Institutional Review Board (IRB) prior to use with participants. The IRB may have additional suggestions or request changes to the language in these documents.

Recruitment letters should begin with any one of the following:

- We are contacting you because you were seen by UNC Health Care or one of our affiliate hospitals or clinics in the past year.
- Your records in the UNC Health Care System indicate you may be eligible to participate in our research study entitled “XXXXXXXXXX”. We are contacting people who have either an xxxx (lab value) or xxxx (specific inclusion criteria)
- You were seen by UNC Health Care in the past year. We are contacting people who are in the xx to xx age range who have been seen by the UNC Health Care System in the past year in order to tell them about a research program that we are doing.
- Based on your medical history, you may be eligible to participate in this study.

Recruitment emails should begin with one of the following

- We are contacting you because you were seen by UNC Health Care or one of our affiliate hospitals or clinics in the past year.
- Your records in the UNC Health Care System indicate you may be eligible to participate in our research study.
- You were seen by UNC Health Care in the past year. We are contacting people who are in the xx to xx age range who have been seen by the UNC Health Care System in the past year in order to tell them about a research program that we are doing.
- Based on your medical history, you may be eligible to participate in a study conducted by UNC researchers.

Considerations when developing an email recruitment message:

- Because email messaging may not be secure or an unintended person may receive a message or open an email message (spouse if joint email or boss if work email address), it is not acceptable to include sensitive information such as a medical condition, lab result, specific clinic or study title in an email message. As such, researchers should only include general statements like those listed above in their email recruitment message.
- If one is able to infer from the information in the email the person’s health condition, the PI may consider only including the recipient’s first name.
- Take steps to dissuade potential recruitment subjects from sending PHI in a response they might send to the sender of the recruitment email (e.g., patient receives recruitment email and responds via email stating “*I have pancreatic cancer and diabetes, do you know if I would I qualify for the study?*”). To address this problem, include a statement such as “*Please do not respond to this email as it is unmonitored*” or “*If you respond to us by email, please do not include any of your medical information in your email as your response may not be sent securely.*”
- Use a Department Email address (like UNCPedsResearch@med.unc.edu) to send the recruitment emails – as opposed to an individual’s email (jerry.scott@med.unc.edu).

Telephone scripts should begin with something similar to the recruitment letters:

- Hello, my name is _____. I am a (student/faculty member/staff member) from the University of North Carolina at Chapel Hill. Am I speaking with _____ (patient's name)? [Verify before proceeding]. I'm calling to tell you about a research study at UNC. The study is ("study title"). This study will test xxxxx in xxxxx patients. Your records in the UNC Health Care System indicate you may be eligible to participate in our research study OR based on your medical history, you may be eligible to participate in our study
- If participant asks "How did you get my name and contact information?"
 - **Answer:** When you check in for care at UNC Health Care, you are given a copy of the Notice of Privacy Practices and asked to sign that you received it. This document describes that, because UNC is a teaching and research institution, your information may be shared with UNC researchers for research purposes provided they first get approval from a research ethics review board called the IRB.
 - **Additional information, if needed.** We received IRB approval to access a limited set of information from your medical records. Specifically, we obtained your xxxx (list variables). This information helped us to know that you might be eligible for our research study.
- If participant states, "but I am not a UNC Health Care patient, I go to Rex (or other) Hospital."
 - **Answer:** UNC Health Care System now includes several affiliate hospitals and clinics, including Rex (or name of other UNC hospital affiliate). So, even though you receive your care at Rex (or other name), your records are part of the UNC Health Care System.

Notes about the CDW-H patient database (not to be included in recruitment letters or emails):

- Subjects do NOT actually sign up for the Carolina Data Warehouse for Health (CDW-H). The names of potential research participants are in the CDW-H by virtue of their having been seen by UNC Health Care (or at an affiliate Hospitals) in last several years.
- One should NEVER say "We are contacting you because you signed up with the Carolina Data Warehouse for Health (CDW-H)."
- Recruitment letters, emails, or telephone scripts should NOT make a reference or describe that patient data or records were provided by the Carolina Data Warehouse for Health. The language used should only reference or describe records coming from the UNC Health Care system.
- UNC Health Care System now includes the UNC Hospitals in Chapel Hill, and multiple affiliate Hospitals and Clinics (Rex, Chatham, Nash, High Point, Pardee, Johnston, Caldwell, Wayne, Lenoir). The data pulled via the CDW could include patients from any of these locations if those hospitals have implemented the Epic Medical Record.