Protocol to use the Registry for Recruiting Study Subjects

**While the Illinois Women’s Health Registry is a program developed and run by the Women’s Health Research Institute at Northwestern University, we invite investigators at all statewide institutions with IRB approved studies to use this recruitment tool.**

1) Investigators who wish to obtain a pool of women for a study need to submit: 1) an application with inclusion and exclusion criteria (this is based on the registry survey instrument), 2) a copy of their IRB approved protocol or provide proof of submission and 3) sign a Statement of Understanding found on page 2 of the application. (1 and 3 is provided in this packet)

2) The Registry Coordinator will review each application to determine that the proposed study has current (or pending) IRB approval, has sufficient protections for subject confidentiality and safety, the appropriateness of using the Registry as a research recruitment tool.

3) Once the investigator has completed the application processes, the Registry Coordinator will create a Service Agreement that will compile all the factors of the query including cost. For Northwestern staff we will request a billing chart string number on the Service Agreement. For researchers at other institutes we will ask for contact information to send an invoice. Once the Service Agreement has been reviewed and signed, your query will be run, which will result in contact information of women that match the selected criteria. The fees are listed on the back of this sheet.

4) A study specific letter will be sent to women who meet the basic criteria of the given study, informing them of their selection as a potential study subject. If there are no objections from a woman after a five day opt-out period, her contact information is released to the investigator (or study coordinator) who will follow up to discuss the study. (Note: PIs and staff members of approved studies will not have direct access to the Registry database. Registry staff will perform database inquiries to determine who may be eligible based on the study’s inclusion/exclusion criteria. Study investigators will only be given necessary contact information regarding participants).

5) After the participant is contacted by an approved investigator, all procedures and confidentiality issues will fall under the investigator’s approved research protocol.

6) Registry participants may or may not elect to become a subject in an approved research study. This will not affect their ability to remain in the Registry database and to be potentially selected for other research projects.

7) All investigators who obtain information from the Illinois Women’s Health Registry will receive a follow-up survey regarding their experiences with the Registry. The purpose of this survey is to obtain an estimate of the number of subjects they were able to recruit from the Registry, and to gauge overall satisfaction with the Registry. The results from this survey will be used for internal benchmarks and process improvements.

Contact:
Registry Coordinator
whregistry@northwestern.edu
800-984-4947

---

1 Our staff is responsible for performing all queries. Charges to run database queries can be found on page 5 of the application.