**Rochester Epidemiology Project**

**Frequently Asked Questions**

**Q:** **What is the Rochester Epidemiology Project (REP)?**

**A:** The REP is a records-linkage system which links together medical records of Olmsted County, MN residents from their primary sources of health care (including Mayo Clinic, Olmsted Medical Center and Rochester Family Medicine Clinic).

* The REP linkage system has been used by hundreds of investigators for developing studies on a wide range of medical conditions.
* Since 1966, this resource has supported projects resulting in over 2,000 publications

**Q: What does “epidemiology” mean?**

**A:** The study of incidence and control of disease in a population.

**Q: What types of studies are done?**

**A:** Most REP studies are chart review studies (looking at the medical record) and therefore do not involve interaction with a patient.

* Sometimes medical records do not have the types of information needed for a specific research question. If this happens, then the researchers may use a patient survey or even ask them to participate in additional testing.
* All REP studies must be approved by the Institutional Review Boards of Mayo Clinic and Olmsted Medical Center prior to a study commencing.

**Q: How do I know if I’m part of the REP?**

**A:** If you receive your health care at a participating institution, such as Mayo Clinic, Olmsted Medical Center or Rochester Family Medicine Clinic, then you will have been asked about Minnesota Research Authorization.

* Since 1997, no one’s medical information can be used for research purposes without his or her authorization.
* Patient confidentiality is very important to the REP!
* All providers participating in the REP ask patients to sign a MN research authorization form.
* If a patient has said “no,” that person’s record cannot be used for research
* In Olmsted County, 93% of Mayo Clinic patients and 95% of OMC patients have authorized use of their medical records for research.
* To find out what your research authorization status is, please contact the medical records department of your provider.
* A patient can change their decision at any time by contacting their health care provider.

**Q: What is Minnesota Research Authorization?**

**A:** Since 1997, (in MN) no one’s medical information can be used for research purposes without his or her authorization.

* To our knowledge, no other state has a similar law (in other states, authorization is not needed to use medical records for research).
* Medical institutions who wish to use patient records for research must ask their patients to sign the MN Research Authorization form.
* If a patient doesn’t fill out a MN Research Authorization form, he or she must be asked a second time to fill out the form. According to the law, if the form is not signed after the second request, the patient’s record can be used for research.
* A patient may change their research authorization status by contacting their medical provider.
* Parents or guardians sign for their children. When children turn 18, they are asked to sign their own MN Research Authorization forms.

**Q: When does MN Research Authorization not apply?**

A: The law applies primarily to chart review studies.

* Researchers may still invite a patient to participate in a special study that focuses on a specific disease, even if he or she refused general research authorization. In this case, the patient will go through the informed consent process.

**Q: I was part of a study a few years ago, but I’ve never heard from them again. Do you know what the status is?**

**A:** Since participation in a study is confidential, we do not know about an individual’s participation status. The best way to follow-up on a study you’ve participated in, is to reach out to the specific study group that originally contacted you.