The Greatest Resource You've Never Heard Of

It's the medical resource behind discoveries that have affected patients around the globe, treasured by researchers and funded by the National Institutes of Health for nearly 50 years: the Rochester Epidemiology Project. This comprehensive medical records pool makes Olmsted County, Minnesota one of the few places in the world where scientists can study virtually an entire geographic population to identify trends in disease, evaluate treatments and find factors that put people at risk for illness — or protect them. And, as it nears the half-century mark, the project is still growing.

Health care providers in seven southeastern Minnesota counties are adding patients' records, more than doubling the number of area residents included. The project has followed a half-million lives since it began. Co-directors Walter Rocca, M.D., a Mayo Clinic neurologist and epidemiologist, and Barbara Yawn, M.D., research director at Olmsted Medical Center, describe how it developed and where it is going in this month's *Mayo Clinic Proceedings*.

"The Rochester Epidemiology Project is unique, especially because of its historical capability. We go back to 1966, and we can look at big chunks of histories of people's lives," Dr. Rocca says. "It's extremely valuable to be able to answer medical questions that have to do with prevention, better care and also with understanding the cost and the effectiveness of our interventions." The project has supported more than 2,000 studies.

Research making headlines in recent years includes:

- The findings that women who had their ovaries removed before menopause are at higher risk of dementia.
- Multiple exposures to anesthesia before age three are linked to more than double the incidence of attention-deficit/hyperactivity disorder.
- Skin cancer is up dramatically in people under 40, especially young women.
- Smoke-free workplace laws save lives.
- Mild cognitive impairment is more prevalent in older men than in older women.
- Traumatic brain injuries are likely more common than had been believed.

Fewer than five percent of Olmsted County's residents opt out. Those who take part can help science without getting poked and prodded or even meeting a researcher. The project can be used to study pretty much any condition; dozens of studies that otherwise wouldn't be possible are under way at any given time. The biggest change the Rochester Epidemiology Project is seeing mirrors the nation's changing demographics. While whites of Northern European descent have long made up most of Olmsted County's population, a new wave of immigration means that 1 in 4 children isn't of European descent, Dr. Rocca says. Currently, researchers looking

for ethnic differences in studies can compare their findings from the project with a much smaller group of ethnically diverse patients, to see whether there are differences or it's a moot point, he says.

The project has its origins in the earliest days of Mayo Clinic. Long before computers existed, Mayo archived patient medical records, believing they would someday prove valuable to researchers. In 1966, Mayo obtained NIH funding to link medical records from healthcare providers across the county, including Olmsted Medical Center and the Rochester Family Medicine Clinic, and the Rochester Epidemiology Project was born. Eventually technology caught up and the records were put on computer. The NIH's National Institute on Aging has funded the project since 2010.

"We recognize the potential for the Rochester Epidemiology Project as a valuable research resource that will enable the scientific community to address public health research questions of importance for the well-being of older Americans," says Chhanda Dutta, Ph.D., chief of NIA's Clinical Gerontology Branch.

Hot areas for future research using the project include looking for socioeconomic factors that may drive illness and patients' responses to treatment or serve as protective factors. Dr. Rocca says Olmsted County residents have a broad range of economic and educational backgrounds. The addition of seven counties also will help researchers study differences between urban and rural populations, another popular area of inquiry right now.

The types of medical information available in the data pool are also growing. The few Olmsted County health providers missing from the project — dentists, optometrists and chiropractors, for example — are being added, and the project is making it easier to analyze immunizations, prescription drug data and the cost of medical services, Dr. Rocca says.

Dr. Rocca is the Ralph S. and Beverley E. Caulkins Professor of Neurodegenerative Diseases Research at Mayo Clinic. He is often invited by other institutions to share information about the project. He has given talks about it in South Korea, France, Uruguay, Brazil and Argentina in recent months.

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