

## Sweden's health data goldmine

It took 5001 pairs of twins to persuade a rheumatology researcher at the Karolinska Institute in Stockholm, Sweden, that smoking helps to cause arthritis. To reach that finding, Per-Johan Jakobsson and a dozen colleagues plumbed Sweden's National Twin Registry, contacted all Swedish twins born before 1958 and obtained blood samples. After correlating genomic information from these samples with data on the twins' smoking history and rheumatoid arthritis status obtained from Sweden's National Patient Registry, a significant link between smoking and arthritis became evident.

"We can do this in Sweden," Jakobsson said with a modest shrug during a seminar at Karolinska on his findings, which were published Nov. 25, 2013. Sweden boasts 90 national registries tracking data on a dazzling array of health issues.

Expanding the registries is now a national priority and funding has expanded nearly fivefold from \$11 million to \$50 million per year. A 2010 government report, *A Review of the National Registers: A Gold Mine in Health Care*, says an investment of \$70 million annually in disease registries, data analysis resources and information technology infrastructure, could allow Sweden to reduce its annual growth in health care spending from an estimated 4.1% to 4.7% and save an estimated \$7.8 billion over ten years.

"We are focusing on registry-based research, looking at risk factors, looking at chronic diseases," explains Katarina Bjelke, director general of research policy at the Ministry of Education and Research. "Public health needs are closely integrated into clinical research strategy."

Sweden has a tradition of collecting epidemiologic data going back more

than two centuries, says Karolinska Institute President Dr. Anders Hamsten. "That, and our highly integrated public health system, has helped us create one of the world's most extensive systems registries for health data."

The secret of Sweden's health data treasure trove, according to Dr. Jonas



Paul Webster

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Ludvigsson, a Karolinska Institute professor and chairman of the Swedish Society of Epidemiology, lies in the use of unique personal identity numbers allowing researchers to link data from millions of people in different registers at the same time. "This gives our studies great statistical power and we are able to detect — or rule out — small effects."

It was possible to build the registries because Swedes "tend to be positive about research and research participation" and "are used to a rather strong state where participation in government-initiated registries is not seen to restrict your freedom," says Ludvigsson. Which is just as well, he adds, because "the Swedish medical registries are part of the nationwide health care, and the government has decided that you cannot opt out from the registries."

Many of the registers, such as the cancer register which was established in 1958, also have rich long-term data. "That means that we have long follow-up and are able to examine exposures that will lead to complications and adverse events as long as 30 or 40 years later." Ludvigsson points to a wealth of inter-generational data collected in a multigeneration register tracking mother-child, sibling and twin relationships as especially important. "This means that we can examine the importance of hereditary factors, of pregnancy exposures on the offspring and also use siblings as reference individuals when we study diseases where, for instance, familial environment is of great importance."

The registries make it "much easier to generate translational projects that move basic scientific findings towards clinical innovation," says Hamsten.

The registers have often figured in Swedish breakthroughs such as the development of the Seldinger catheter, the pacemaker, the gamma knife, growth hormones, and numerous drugs. In the past year, the registers have spawned published research offering insights into diabetes and ethnicity, socio-economic risk factors for injuries in children, adherence to drug label recommendations, drug interaction avoidance, family history as a predictor of hospitalization for hypertension, adverse events after immunization of adolescent girls with quadrivalent human papillomavirus vaccine, and the roles played by neighbourhood, family, and childhood in adolescent epilepsy.

"Sweden," Hamsten enthuses, "is a goldmine for epidemiological research." — Paul Christopher Webster, Stockholm, Sweden.

CMAJ 2014, DOI:10.1503/cmaj.109-4713