



## KEY POINTS

### Cd-link data release steps

- Research proposal submitted
- Privacy and feasibility assessment
- Investigator and analyst define plan
- Personal identifiers are removed, scrambled
- PARAT applied, quasi-identifiers modified
- Minimum 3-5 patients in data set with same characteristics
- De-identified data burned to disk
- Disk shared with investigators

**“Khaled El Emam has a great reputation and having him and his product behind what we’re doing, I think was very impressive, especially at the Privacy Commission level.”**

**Dr. Craig Earle**



## ONTARIO CANCER DATA LINKAGE PROGRAM (CD-LINK)

“Taking data where it has never gone before” could be the motto of the Ontario Cancer Data Linkage (cd-link) Program that is housed in the Institute for Clinical Evaluative Sciences (ICES).

The cd-link program was established in 2010 under the guidance of Dr. Craig Earle who returned home from a prominent career in the U.S to create Canada’s version of the Surveillance, Epidemiology, and End Results (SEER) Program.

Dr. Earle’s vision was to link Ontario’s rich cancer data resources and to provide the de-identified data directly to health services researchers. Consulting widely to ensure the maximum privacy for Ontario residents for a project that had never been undertaken in the province, Dr. Earle was advised to rely on the American HIPAA Safe Harbor privacy standards and to then apply statistical analysis to ensure that the data could not be re-identified.

To assess the risks of re-identification and to de-identify the data, Dr. Earle selected the Privacy Analytics Risk Assessment Tool (PARAT). For taking every possible step to ensure data could not be re-identified, key government officials expressed their approval for the decision.

“It’s peace of mind knowing that we’ve done everything possible to meet industry standards for de-identification,” says Dr. Earle, who has approved eight projects in the first year and has two more on the waiting list.

Prior to the adoption of PARAT, access to research data was complicated and costly. Researchers seeking access to cancer data would have to travel to Toronto, plan on lengthy stays inside secure offices and mutter a little prayer, hoping not to forget anything before making the journey home. Since the implementation of PARAT, all that has changed for cd-link researchers who submit a research proposal, define a plan, wait for the application of PARAT and then receive a copy of the disk of the de-identified research data.

Removing the barriers imposed for geographic, affiliation and financial reasons, the cd-link program provides access to nine datasets with more to come now that the precedent has now been established to bring in other data sets.

Dr. Earle has ambitious goals for the program, taking a data access concept that was limited to a single site and expanding it across the country, thanks in large part to the application of PARAT.

“Having the PARAT procedures in place could conceivably make it so that other provinces could consider a similar sort of data release mechanism. That’s something I’m just starting to explore. As it reassured people in Ontario, hopefully it can reassure people in British Columbia, Manitoba, wherever.”

**Trust PARAT for  
Re-identification Risk  
Management and  
De-identification**



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