

OVERVIEW

The Challenge:

Providing anonymized data that can be used to create innovative healthcare solutions while protecting patient privacy.

The Solution:

Determining the level risk of re-identification using Privacy Analytics' software and sharing the data with budding entrepreneurs.

The Benefit:

De-identified data that enables the development and testing of innovative healthcare solutions.

cd-link Program: Placing Ontario's Cancer Data in the Hands of Researchers

The Ontario Cancer Data Linkage Program called - *cd-link* - is an initiative of the Ontario Institute for Cancer Research and the Cancer Care Ontario Health Services Research Program. Through a collaborative agreement between the Institute for Clinical Evaluative Sciences (ICES) and Cancer Care Ontario (CCO), *cd-link* is a data release program whereby cancer data is de-identified and made directly accessible to health services researchers.

The *cd-link* program was established in 2010 under the guidance of Dr. Craig Earle, Director, Health Services Research Program, Cancer Care Ontario and the Ontario Institute for Cancer Research, whose vision was to make ICES cancer data directly available to healthcare researchers. In order to put the *cd-link* plan into effect, Earle needed to establish a way of safeguarding and de-identifying patient-level information in accordance with Ontario (PHIPA) and US (HIPAA) privacy legislation.

"Having the Privacy Analytics' methodology procedures in place could conceivably make it so that other provinces could consider a similar sort of data release mechanism... As it reassured people in Ontario, hopefully it can reassure people wherever." - Dr. Craig Earle

Turning to the Privacy Experts

Earle selected Privacy Analytics and its enterprise software to measure and manage the re-identification risk of data release. More specifically, Privacy Analytics' software masks and de-identifies personal information using a risk-based approach that optimizes the analytic utility of anonymized datasets. The data release process is then automated. This process not only removes the complexity but also lowers the risk and cost of ensuring that the data is not re-identified.





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Innovative Solutions to Expand Cancer Research

Privacy Analytics has helped ICES establish a new data release mechanism for direct access to anonymized patient-level data. It has also supported the infrastructure needed to create satellite sites for ICES at Queen's University, Ottawa Health Research Institute, and the University of Toronto, with a wave of new centres likely to occur in the future.

It is estimated that Ontario ICES will lead to a 50 per cent increase in the number of cancer health services researchers working with linked population datasets in the next five years. Potentially, this model of data access for research will attract new researchers into the field of cancer health services research and could be broadened to include other diseases and expanded to other provinces.

