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Institute for Clinical Evaluative Sciences (ICES) Exploratory Data & Analytic Services Private Sector Pilot Project

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Objectives

Prior to the launch of ICES Data & Analytic Services (DAS) in March 2014, only ICES scientists and analysts could access ICES data, and data could only be accessed at physical ICES locations. The DAS infrastructure, which allows public sector researchers to work with coded record level data remotely through a secure virtual environment, together with broader trends including high profile reports that call for increased access to data and the Ontario government's Open Data initiative, prompted ICES to launch a pilot project to explore potential DAS work with the private sector.

Approach

Three mandatory principles were established for all work with the private sector: (i) alignment with ICES' mission, vision and values; (ii) transparency; (iii) private sector work must not detract from ICES' research institute work. The pilot included: a jurisdictional scan; informal conversations with private sector organizations to determine potential services/studies of interest; extensive discussions with data partners; the selection and conduct of two pilot studies; focus groups with members of the general public and scientists; external advice on business model options; and an external evaluation of the pilot. No changes to data sharing agreements or ICES processes were required as work with the private sector and public sector are equally allowed under Ontario law.

Results

The two pilot studies were successfully completed. The first study "The disease burden of gout in Ontario: A real world data retrospective study" was performed by researchers at IMS Brogan (a healthcare analytic services provider) who were provided with access to coded record-level data using the DAS iDAVE

environment and performed their own analyses. In the second pilot study, "The impact of adherence to biologics on health-care resource utilization in rheumatoid arthritis", Janssen researchers established the research question and study design, and DAS staff and scientists provided advice about data holdings, performed the analyses, and provided Janssen and three government-funded decision making bodies with results tables. Research Ethics Board approval was required for both studies, and both private sector organizations are in the process of publishing findings.

Conclusion

ICES was able to work with private sector organizations without compromising the three principles. Based on the evaluation of the private sector pilot, and the findings from the focus groups, ICES will begin offering limited analytic services to private sector researchers beginning June 2016 under ICES' existing corporate structure, and bring recommendations regarding ongoing operations to the ICES Board in June 2017.

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