

Data Sharing: Opportunities for Investigators

New Investigators Course 11 August 2017

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Institute of Medicine Sharing Clinical Trial Data: Maximizing Benefits, Minimizing Risk



Stakeholders in clinical trials should foster a culture in which data sharing is the expected norm and should commit to responsible strategies aimed at maximizing the benefits, minimizing the risks, and overcoming the challenges of sharing data for all parties.



Institute of Medicine Sharing Clinical Trial Data: Maximizing Benefits, Minimizing Risk



Stakeholders in clinical trials should foster a culture in which data sharing is the expected norm and should commit to responsible strategies aimed at maximizing the benefits, minimizing the risks, and overcoming the challenges of sharing data for all parties.

Holders of clinical trial data should mitigate the risks and enhance the benefits of sharing sensitive clinical trial data by implementing operational strategies...



Controversy

#researchparasite

"people who had nothing to do with the design and execution of the study but use another group's data for their own ends, possibly stealing from the research productivity planned by the data gatherers...





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Our preferred term

"collaborator"





Examples: analyses conducted at CCTG

Location of colon cancer as a prognostic and predictive factor

- Led by Stephanie Brulé, Oncology Resident
- Utilized data from CO.17 (cetuximab)
- Published European Journal of Cancer 2015

Impact of BMI in adjuvant breast cancer trials

- Led by Rinat Yerushalmi, Oncology Fellow
- Utilized data from MA.5, MA.12, MA.14, MA.21, MA.24, MA.27
- Published Annals of Oncology 2017

Net benefit regression in clinical trial health economic analyses

- Led by Jeffrey Hoch, PhD Health Economics
- Utilized data from LY.12, CO.17 and BR.21
- Manuscript in preparation



Examples: analyses led outside CCTG

Outcomes of patients with refractory aggressive B-cell lymphoma

- Included data from LY.12 in pooled SCHOLAR1 analysis
- Analyses conducted by Kite Pharma with input from investigators
- Published Blood 2017

Impact of radiotherapy timing in small cell lung cancer

- Utilized BR.6 data in meta-analysis
- Analyses led by RTT-SCLC Collaborative Group
- Published Annals of Oncology 2016

Development of Canadian cancer-specific utility weights

- Utilizing data from trials with QoL and health utilities collected
- H McTaggart /ARCC/ MAUCa consortium led, CCSRI funded
- Work underway



Reciprocal Data Sharing for Mutual Benefit

CCTG data sent to Institute of Clinical Evaluative Sciences (ICES)

- Provided proof of concept for data linkage and validated high quality of Ontario administrative data
- Potential role for administrative data in long term clinical trial follow up, and for provision of real world resource utilization
- Plan to utilize clinical trial data to develop algorithms to enhance utility of administrative data

Statistics Canada and Provincial Cancer Agencies

 Project in development for administrative data to be made available to CCTG on consenting patients in the LY.12 trial

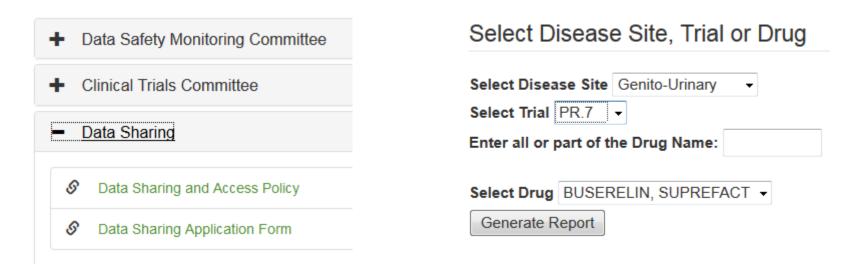




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New dedicated data sharing portal with search engine in development

Committed to Overcoming the Challenges

Canadian Cancer Trials Group

Committed to expanded data sharing, with appropriate safeguards

- Data sharing policy and consent forms updated
- Clarity of mutual expectations: data sharing agreements
- Difficulties understanding data fields: develop data dictionaries
- Uncertainty of where to find / how to interpret data:
 communication at all stages of secondary analyses conduct
- Developing new dedicated IT platforms
- Seeking funding to support



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