

Data Sharing: Opportunities for Investigators

New Investigators Course

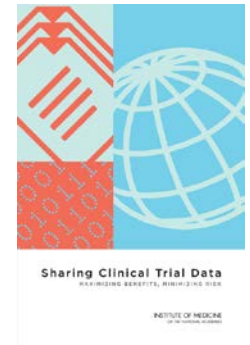
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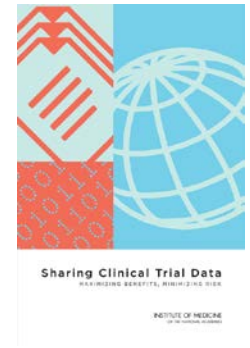
Institute of Medicine Sharing Clinical Trial Data: Maximizing Benefits, Minimizing Risk



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
- Published BMC Cancer 2019

Examples: analyses led outside CCTG

Outcomes of patients with refractory aggressive B-cell lymphoma

- Included data from LY.12 in pooled SCHOLAR-1 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

Hypothetical patient surveys: 90% acceptance across

- Oncology patients in Ontario¹ & Cardiology patients in Quebec²

CCTG data sent to **Institute of Clinical Evaluative Sciences (ICES)**^{3,4}

- *Health services* - enhance utility of administrative data
- *Clinical trials* - long term follow up, real world resource utilization
- *Patients* – minimizes inconvenience and expense

Statistics Canada and **Provincial Cancer Agencies**⁵

- Long-Term Innovative Follow-up Extension (LIFE) study underway
- Admin data for consenting patients to be provided to CCTG

¹Hay, Current Oncology 2017

²Avram, Int J Cardiology 2018

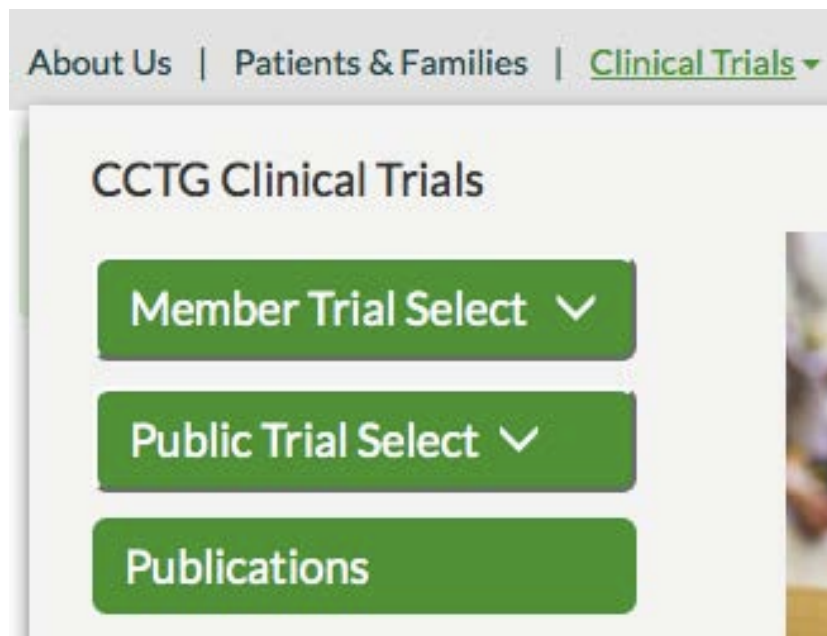
³Hay, Clinical Trials 2019

⁴Hanna, J Onc Pract 2019

⁵Hay ASCO 2018, manuscript in preparation

How to make a data sharing request

How to find published CCTG trials



- Journal publications
- Abstracts
- Books

Select Publication Type

Select Disease Site

Select Trial

Enter all or part of the Drug Name:

Select Drug

Generate Report

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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