

What's in our way?

The challenges and recommendations of using real-world oncology data to generate real-world evidence for drug funding decisions.

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Conflict of Interest Disclosure

I have no actual or potential conflicts of interest in relation to this topic or presentation.

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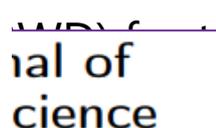
The SPOR-Canadian Data Platform: a national multi-jurisdictional research

Lindsey Todd Dahl^{1*}, Alan Katz², Kimberlyn McGrail³, Brent Davidson McDonald⁷, P. Alison Paprica⁸, Michael Schull⁹, Jennifer D Walker¹⁰,

Lucyk et al. *BMC Medical Informatics and Decision Making* (2015) 15:69
DOI 10.1186/s12911-015-0196-9

Factors affecting access to administrative health data for research in Canada: a study protocol

Cynthia Kendall^{1,2,*}, Adrian R Levy³, Geoff Porter², Elaine Gibson⁴, and Robin Urquhart^{2,3}



RESEARCH ARTICLE

Open Access



Administrative health data in Canada: lessons from history

Kelsey Lucyk^{1*}, Mingshan Lu², Tolulope Sajobi¹ and Hude Quan

ORIGINAL RESEARCH

WILEY

Data variability across Canadian administrative health databases: Differences in content, coding, and completeness

Carla M. Doyle¹ | Lisa M. Lix² | Brenda R. Hemmelgarn^{3,4} | J. Michael Paterson^{5,6,7} | Christel Renoux^{1,8,9}

Health Information & Analyzing Health Information in Canada

November 2002

Dr. George Kephart
Dalhousie University

International Journal of Population Data Science

Journal Website: www.ijpds.org



Challenges Associated with Cross-Jurisdictional Analyses using Administrative Health Data and Primary Care Electronic Medical Records in Canada

Katz, A¹, Enns, JE¹, Wong, ST², Williamson, T³, Singer, A⁴, McGrail, K⁵, Bakal, JA⁶, Taylor, C¹, and Peterson, S²



Value-based decisions from Real World Evidence



CanREValue Collaboration: Goal

To develop a framework for the generation and use of RWE of cancer drugs to enable:

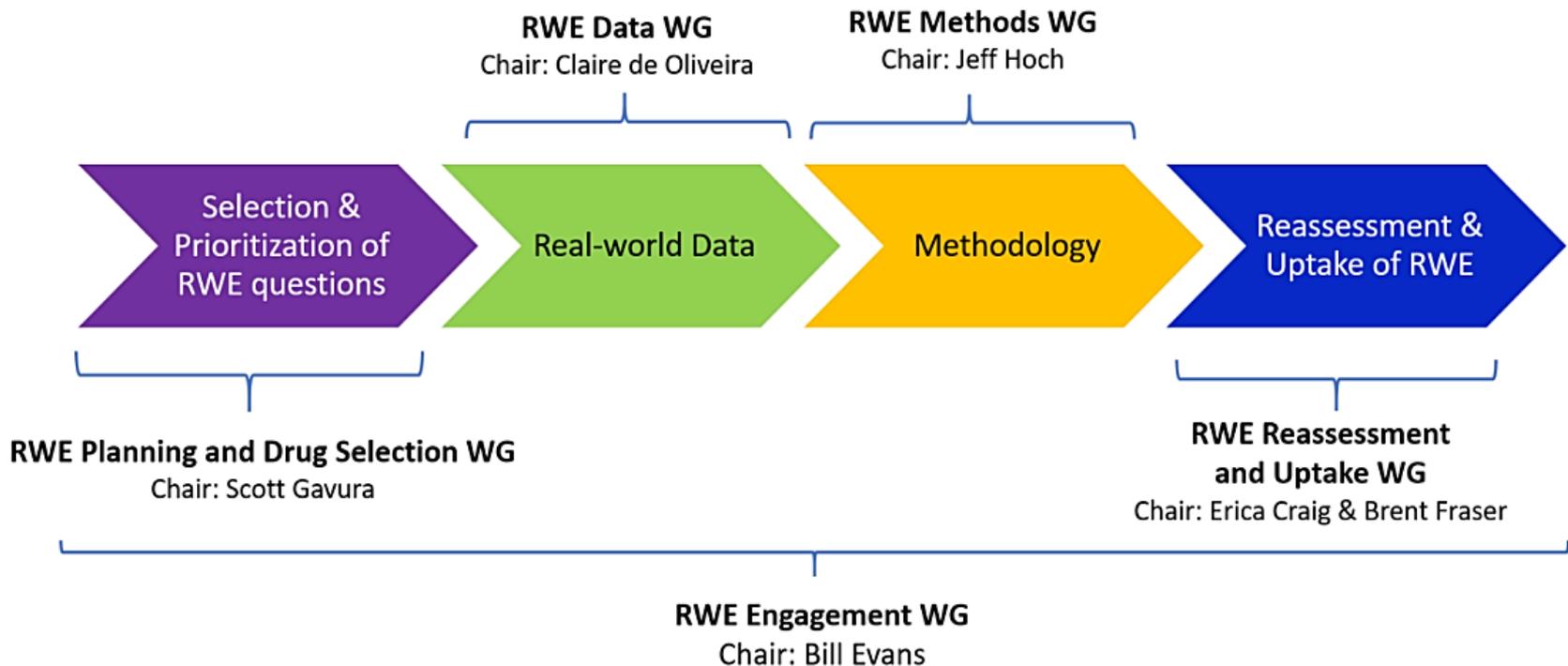


Reassessment of cancer drugs by recommendation-makers



Refinement of funding decisions or renegotiations/
disinvestment by decision-makers/payers across Canada

CanREValue Working Groups



CanREValue Data Working Group

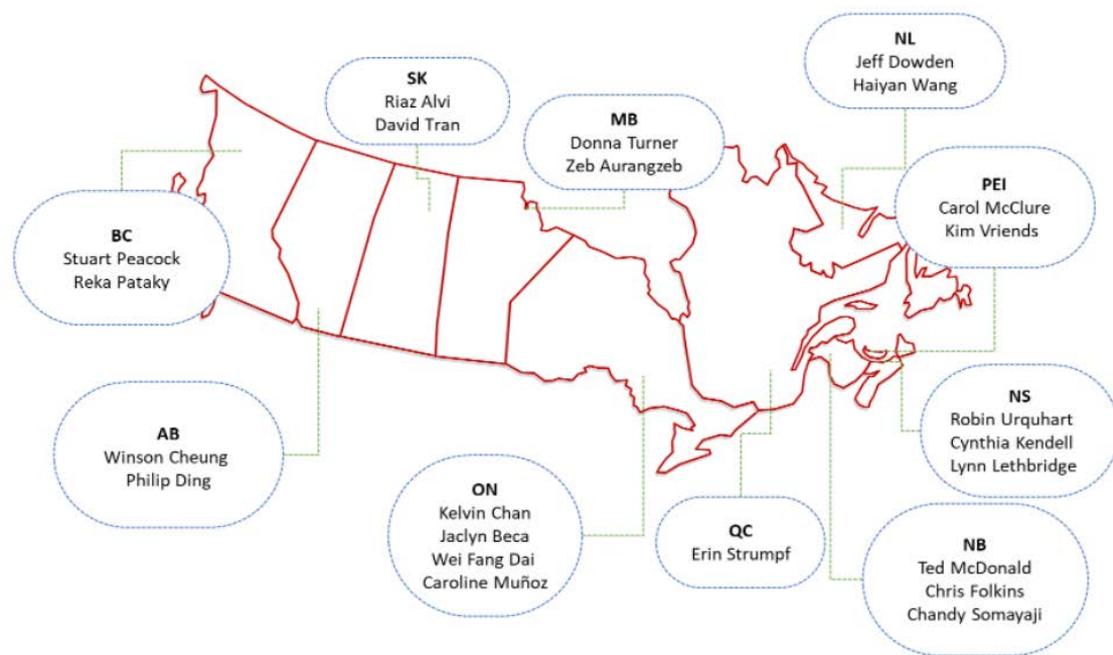
Chaired by Dr. Claire de Oliveira

Key Projects:

1. Mapping Canadian Data Assets for RWE generation

2. Demonstration Project: Multiprovince retrospective, cohort study comparing pertuzumab + trastuzumab vs. trastuzumab for treatment of metastatic breast cancer to assess

- Effectiveness
- Safety
- Cost-effectiveness



Data WG Approach

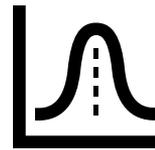
- From June-July 2021, 14 Data WG members in 10 provinces surveyed
 - Survey #1 sent in June 2021 – asked Data WG members to identify specific challenges related to RWD for RWE generation encountered while conducting the Demonstration Project within their own province
 - Survey #2 sent in July 2021 – asked Data WG members to provide recommendations and potential solutions to address the challenges they identified.
 - Survey responses were collected, and main themes were identified and summarized for both the challenges and recommendations.
- 12 Data WG members in 9 provinces completed the surveys

Main challenges

4 main challenges of using oncology RWD for RWE generation include:



Data Accessibility



Analytics



Data Availability



Logistics & Resources

1. Data Accessibility

Challenges

- Necessary datasets held by different data custodians
- Limited access to oncology RWE specific data elements
- Data access applications requiring different levels of information
- Situational factors: COVID-19, implementation of new data custodian

Recommendations

- Implementing centralized data holdings
- Incorporating RWE generation into provincial decision-maker operations
- National harmonized data access agreement
- Develop a national set of standards for conducting RWE studies

2. Data Availability

Challenges

- Selective reporting to centralized data holders
- Missing variables specific to real-world oncology studies
- Variation in data missingness between jurisdictions

Recommendations

- Using data from private and industry data holders
- Increasing data harmonization between data sources
- Implementing data standardization practices

3. Analytics

Challenges

- Cohort creation
- Bias adjustment using demographic & clinical variables
- Covariate and outcome identification

Recommendations

- Algorithm creation for missing covariate and outcome variables
- Use of advanced analytic methods such as natural language processing or AI

4. Logistics & Resourcing

Challenges

- No staff engaged full-time on the Demonstration Project
- Multiple, competing demands among participating analysts

Recommendations

- Employ a proactive, as opposed to reactive, approach to resource planning for future projects

Conclusion

- Challenges to using RWD for RWE generation exist and create barriers to the robustness and timeliness of RWE.
- Potential solutions to challenges can be achieved by engaging with stakeholders to collaborate to achieve these solutions.
- The CanREValue Collaboration continues to work together to demonstrate the potential of RWD for RWE generation that is used for oncology drug funding decisions.

Thank you!

We would like to connect with you!

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Please email us at: canrevalue@cc-arcc.ca

Please follow us on Twitter at: @CanREValue