

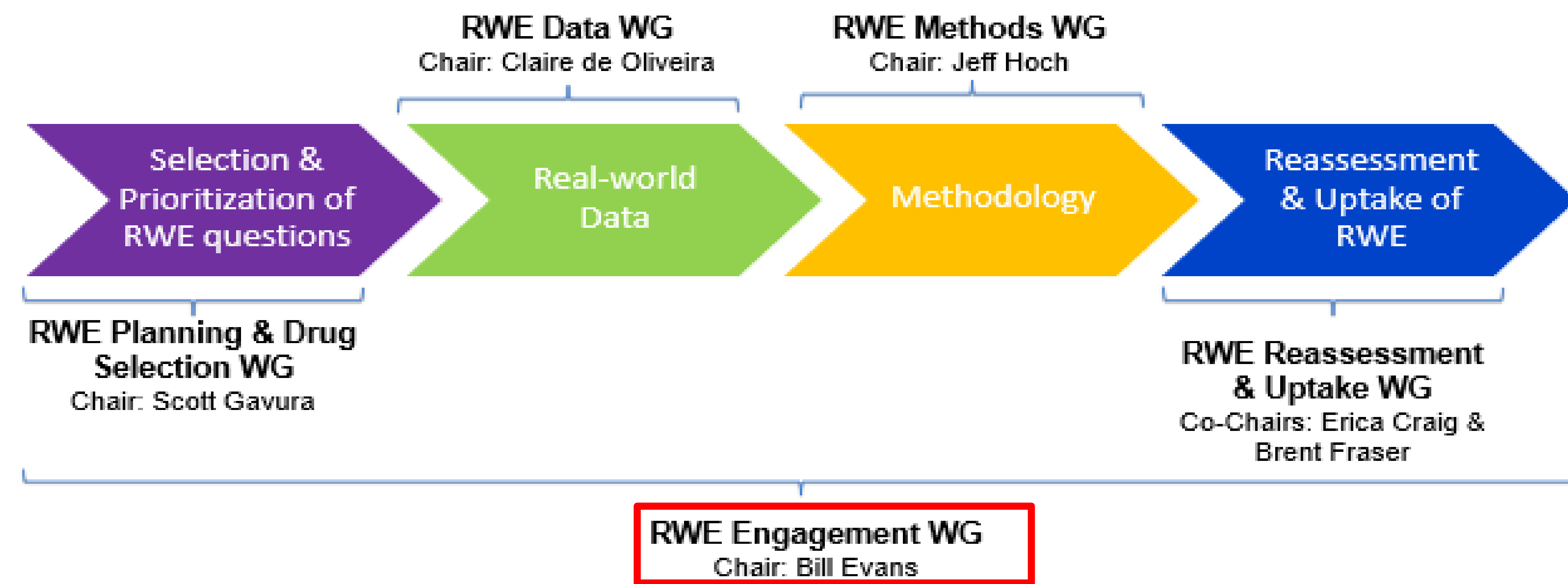
## Engaging Patients in the CanREValue Initiative: Processes and Lessons Learned

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### BACKGROUND & PURPOSE

- The Canadian Real-world Evidence for Value of Cancer Drugs (CanREValue) Collaboration was established in 2017 to develop a framework to generate and use real-world evidence (RWE) for the evaluation of the effectiveness and safety of cancer drugs following their initial health technology assessment (HTA)



- The goal of the consultations was to seek input and feedback on the key policy issues (Policy Working Group (WG) interim report) and data access issues (Data WG interim report)

### METHODS

- An organizing committee comprised of prominent patient representatives (LB, ME, SM, CS and VM) identified patients, caregivers, advocacy leaders and/or individuals engaged in research of patient-related issues interested in reviewing and discussing the Policy and Data interim WG reports
- The following key issues were identified by the organizing committee to be of greatest importance to patient representatives:

<b>Policy Interim WG Report</b>	<ul style="list-style-type: none"> <li>Definition of RWE</li> <li>Triggers for undertaking RWE studies</li> <li>Delisting as a potential outcome from an RWE assessment</li> <li>CanREValue framework's role in conditional recommendations</li> </ul>
<b>Data Interim WG Report</b>	<ul style="list-style-type: none"> <li>Concerns about data access</li> <li>"Missing" data elements in publicly accessible provincial databases</li> </ul>

### FEEDBACK & LESSONS LEARNED

- Two virtual consultations were held in August and October 2021 with over 20 patient representatives from across Canada
- Engaging patient representatives proved to be an enriching opportunity as the CanREValue Collaboration not only received valuable feedback on the RWE framework but also learned important lessons for effective patient engagement moving forward

#### Feedback on Policy and Data Access Issues

Patient representatives shared their preferences and identified gaps in important endpoints/outcomes and provided insight on areas of greatest importance and of value to patients, such as:

- RWE Framework should not impede access to new drugs and should be used to support conditional approvals
- National initiative needed to standardize data definitions, to identify essential new data elements (e.g., performance status, quality of life (QoL) data) and improve capacity of provinces to collect these data
- Balance needed between early access and maintenance of high-quality evidence in support of the value of new therapeutics
- Patient relevant endpoints (e.g., QoL, disease-free survival and progression-free survival) should be captured in provincial datasets

#### Engaging Patients: Lessons Learned

The following lessons learned help to achieve effective and meaningful engagement:

- Collaborating with well-known Canadian patient leaders to form an organizing committee was helpful in identifying patient representatives and defining the topics of greatest interest to patients and caregivers
- Providing adequate time and a supportive environment fostered open and honest communication
- Preparing and sharing biographies helped to increase familiarity and trust in a virtual setting
- Monitoring satisfaction and being receptive to revising engagement strategies to reflect the needs of participants is important. Ex. feedback from the initial session led to an adapted second consultation format: two simultaneous breakout groups to allow greater opportunity for discussion.