Canadian Organization for Rare Disorders

Drawing the Blueprint for Canada's Rare Drug Program 2022 - Winter 2021

Webinar 7

What Canada Can Learn from Other Countries ... or Not

January 29, 2021

Countdown to Canada's Rare Drug Strategy 2022: Webinar Series

WEBINAR 7

Jan 29

@ 11AM (EST)

How Other Countries Provide Access to Rare Disease Drugs: What Canada can Learn … or Not

WEBINAR 8

Feb 12

@ 12PM (EST)

Informed Guide to Engaging in National Strategy for High-Cost Drugs for Rare Diseases

WEBINAR 9

Feb 18

@ 6 PM (EST)

Informed Guide to Engaging in National Strategy for High-Cost Drugs for Rare Diseases

WEBINAR 10

Feb 26

@ 12PM (EST)

Rare Disease Day

CORD Canadian Organization for Rare Disorders

Rare Disease Day Conference

From Draft to Action Plan

March 9 - 10, 2021

RARE DISEASE DAY®

Consultation Dates: January – September 2021

- Jan – Feb 2021: CORD ”Drawing the Blueprint” Webinar Series
- Jan – Mar 2021: Health Canada Public Consultations
- March 9 – 10, 2021: Rare Disease Day Conference ”From Draft to Action Plan”
- April 2021: Consolidated Design
- Jun – Jul 2021 Public Consultations
- Aug 2021: Collaborative Document

🚀 Jan 1, 2022: Ready to Launch

CORD Canadian Organization for Rare Disorders

National Strategy for High-Cost Drugs for Rare Diseases Online Engagement

Government of Canada / Gouvernement du Canada

1. Complete the online **questionnaire**
2. Send a written submission via **email** or **mail**
3. Participate in a virtual **public town hall**

Public Town Hall #1	February 9, 2021	3:00 – 4:30pm	Bilingual
Public Town Hall #2	February 25, 2021*	7:00 – 8:30pm	Bilingual
Public Town Hall #3	March 3, 2021*	1:00 – 2:30pm	French
Public Town Hall #4	March 12, 2021	10:00 – 11:30am	Bilingual
Public Town Hall #5	March 23, 2021	3:00 – 4:30pm	Bilingual

To find out more about this consultation on the **National Strategy for High-Cost Drugs for Rare Diseases**, please click on the following link: https://canada.ca/en/health-canada/programs/consultation-national-strategy-high-cost-drugs-rare-diseases-online-engagement.html

Canada

Webinar 7: Discussion Guide

Question 1: There could be a “trade-off” between immediate access to a new drug and short-term assessment based on real-world experience versus assessment prior to real-world access with relatively long-term access. Which is the better pathway for the rare disease drugs that you have familiarity with? Why?

Question 2: When should patients or parents be involved in a managed entry agreement? Who should decide the criteria for “starting and stopping” and who should decide whether a specific patient is meeting criteria to start or stop?

Question 3: How does Canada’s approach compere to plans of the five countries presented here? What could Canada learn?

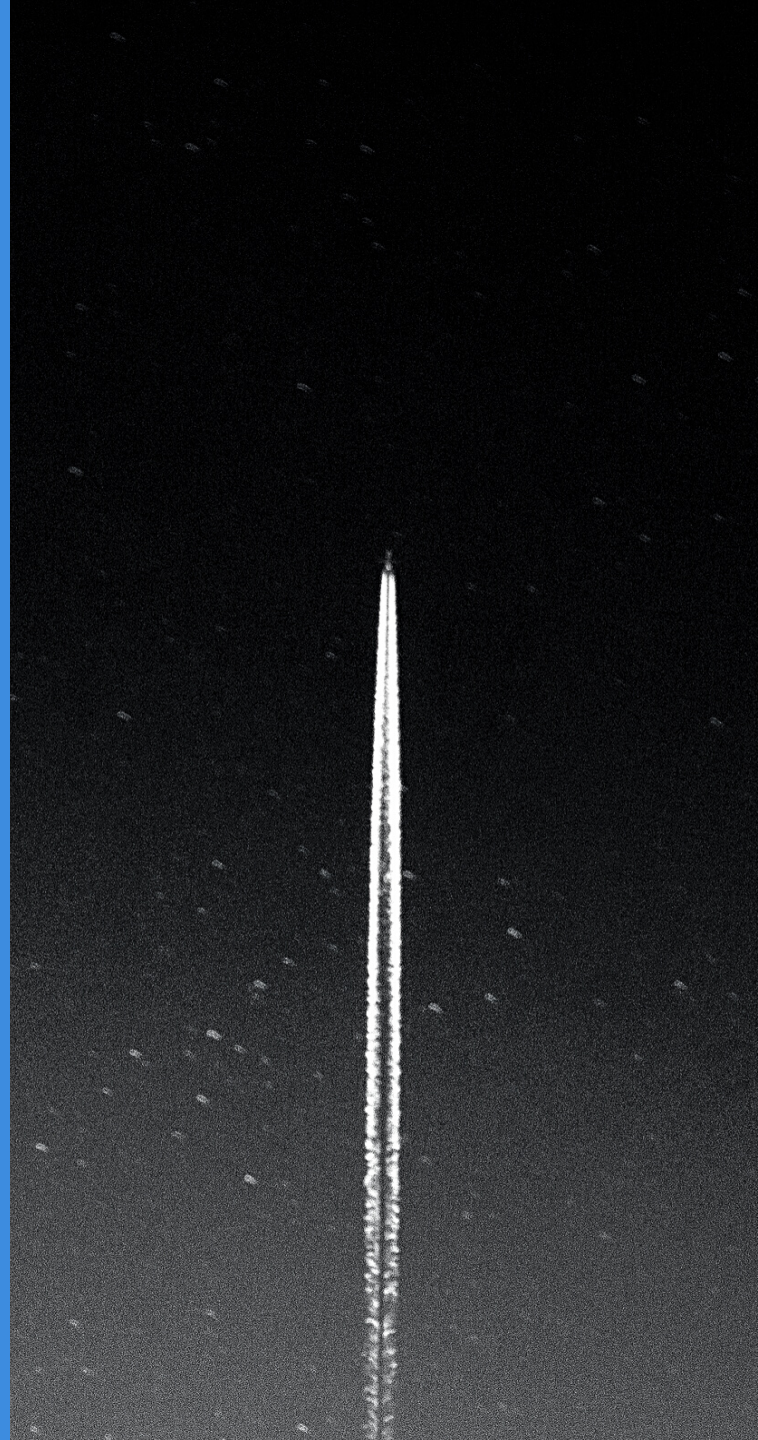
Webinar 7: Lead panel

Line Up:

Presenter: Tania Stafinski, University of Alberta

Discussion Panel:
- Norm Berberich, Takeda
- Angela Diano, Alpha1 Canada
- Ken Chapman, University of Toronto

Moderator: Durhane Wong-Rieger, CORD



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CORD Rare Drug Program
Webinar 7 Poll

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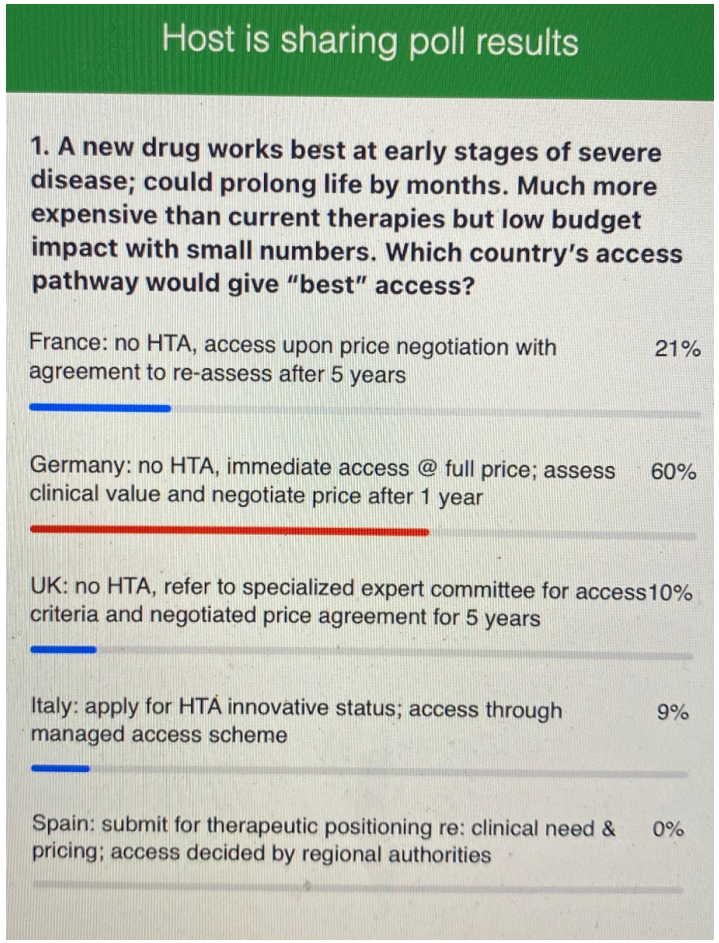
Poll #1 - Results



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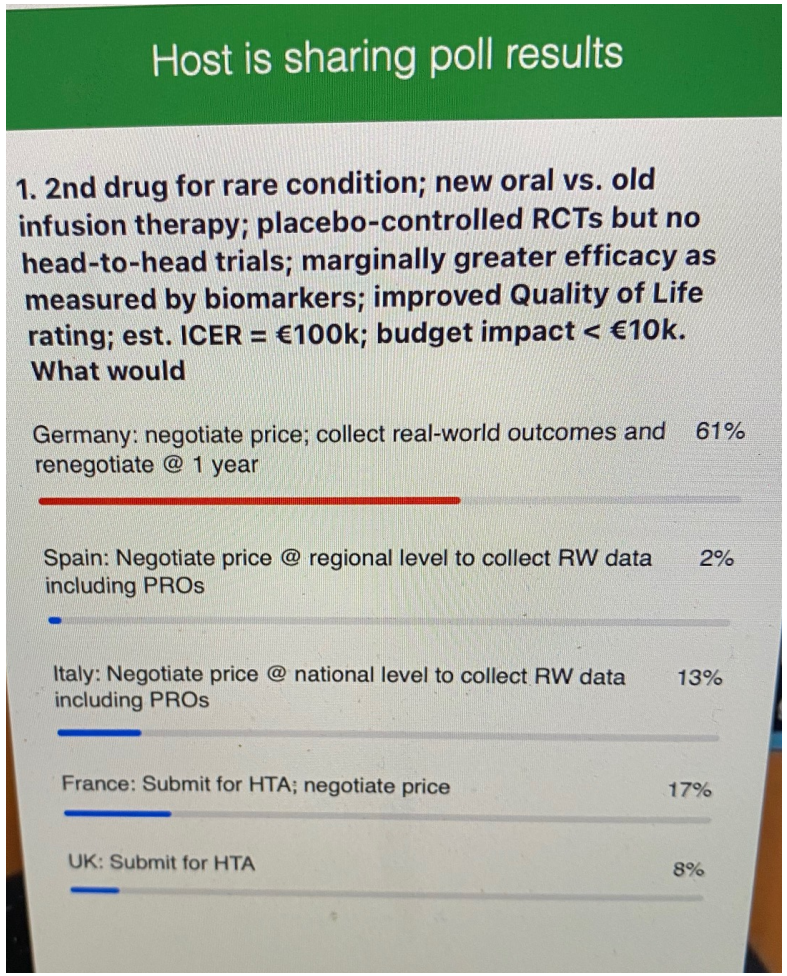
Poll #2 - Results



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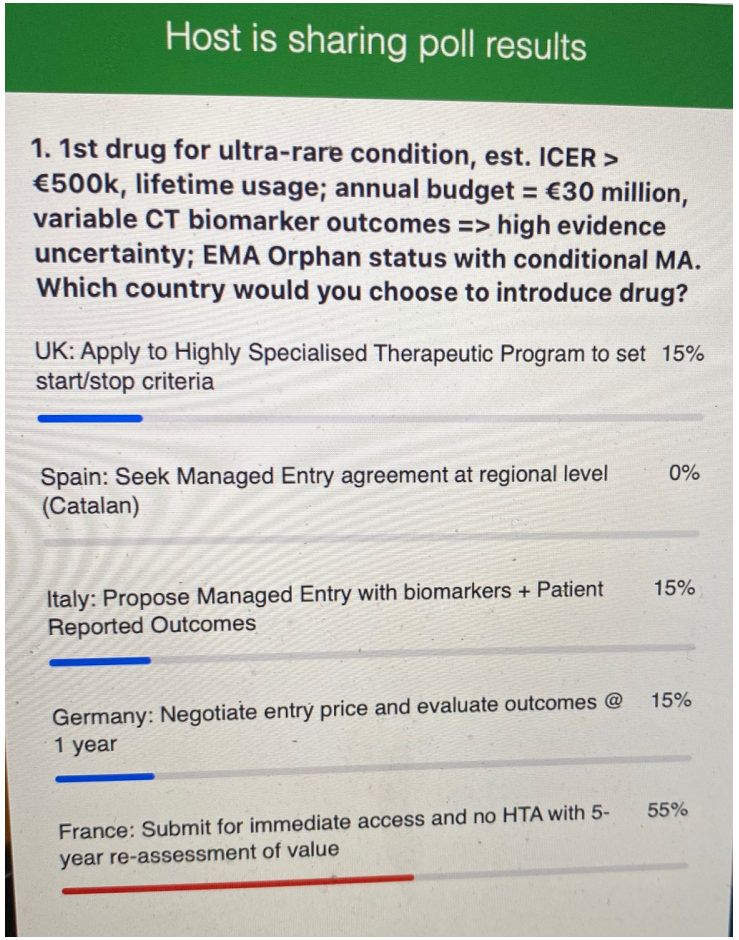
Poll #3 - Results



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