Canadian Organization for Rare Disorders

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

Webinar 6

What We Heard ... Where Do We Want to Go?

January 15, 2021

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

WEBINAR 1
OCT 9
@ 12PM (ET)

Time for a Canadian Orphan Drug Policy

WEBINAR 2
OCT 23
@ 12PM (ET)

Preventive & Risk Reduction Therapies

WEBINAR 3
NOV 6
@ 12PM (ET)

PMPRB: Friend or Foe – Rare Disease Drug Strategy

WEBINAR 4
NOV 20
@ 12PM (ET)

Re-Imagining Canada's Rare Drug Strategy

WEBINAR 5
DEC 4
@ 12PM (ET)

Leave No one Behind: Rarest of the Rare

CORD Canadian Organization for Rare Disorders

ONE-DAY LAUNCH OF A NATIONWIDE CONVERSATION

DECEMBER 16, 2020

11:00 AM – 5:00 PM ET

Designing the Blueprint for pan-Canadian Rare Drug Program

Why Now? Canadians have the Opportunity of a Lifetime to design the world's best Rare Drug Program directed to assure patients have access to today's and tomorrow's therapies. The Canadian government has committed $1 billion to set up Canada's Rare Disease Drug Strategy, with on-going investment of $500 million each year. The Rare Drug Program will be grounded in Canada's Rare Disease Strategy.

What is the Vision? The pan-Canadian Rare Drug Program will assure innovative and essential rare therapies are delivered to patients as soon as possible and consistent with Canadian principles of accessibility, comprehensiveness, universality, portability, and publicly accountable administration.

What is the Task? Stakeholders from all sectors will engage in a structured, informed conversation to design a blueprint for a pan-Canadian Rare Drug Program that will set the course for 10 months of cross-Canada dialogue to arrive at a plan for implementation by January 2022.

Consultation Dates: January – September 2021

- Jan – Feb 2021: CORD ”Drawing the Blueprint” Webinar Series
- March 2021: Rare Disease Day ”From Draft to Action Plan”
- Jan – Mar 2021: Health Canada consultations
- 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

Webinar 6: Crowdsourcing Key Issues on Pan-Canadian Rare Drug Program

Discussion Guide

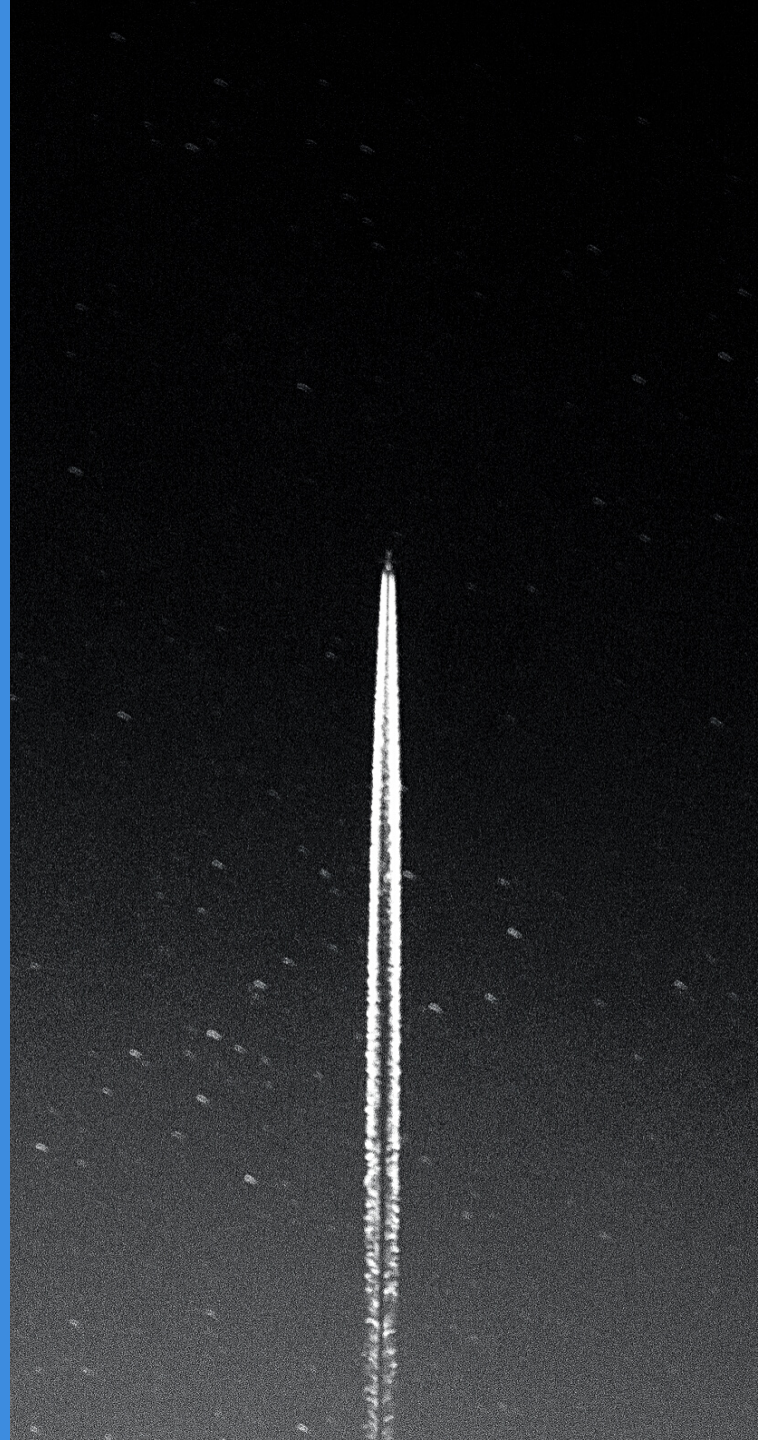
- What Was Said – thus far
  - Feedback: Fall 2020 consultations
  - Interim Results: January 2021 Survey
- What Is Being Said – reflections right now
  - Lead stakeholder panel
  - All of us

Webinar 6: Lead panel

Panelists

- Jason Field, Life Sciences Ontario
- Kim Angel, MPS Society
- Bob McLay, Sobi Canada

- Moderator: Bill Dempster, 3Sixty Public Affairs
- Moderator: Durhane Wong-Rieger, CORD

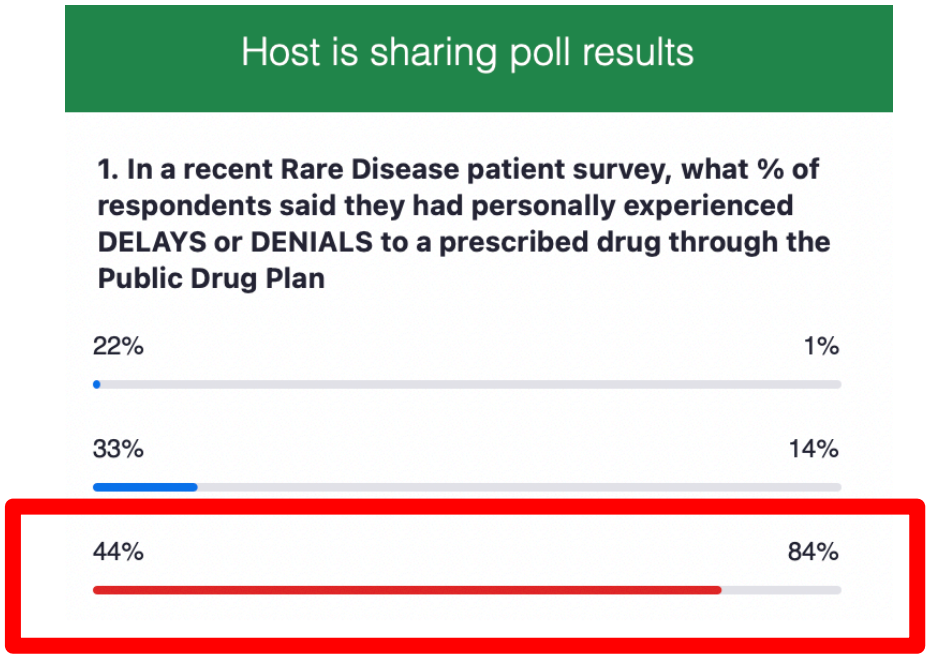


CORD Rare Drug Program
Webinar 6 Poll

Canadian Organization for Rare Disorders

Question #1 - Results

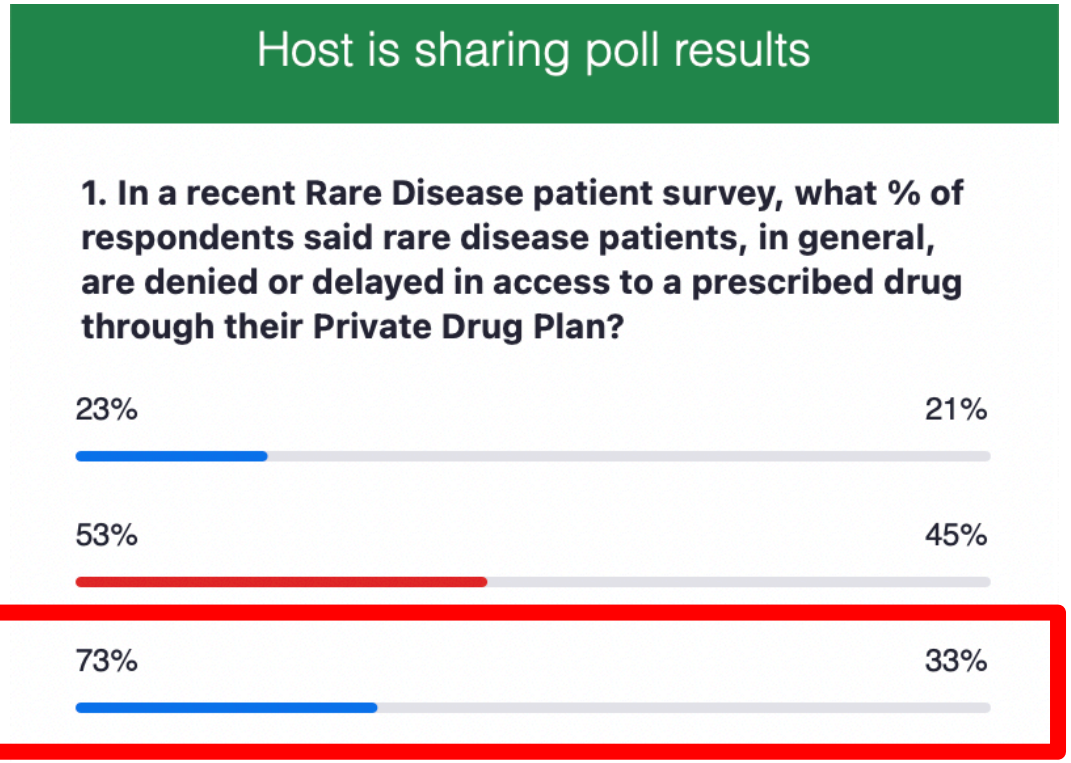
In a recent Rare Disease patient survey, what % of respondents said they had personally experienced DELAYS or DENIALS to a prescribed drug through the Public Drug Plan



Canadian Organization for Rare Disorders

Question #2 - Results

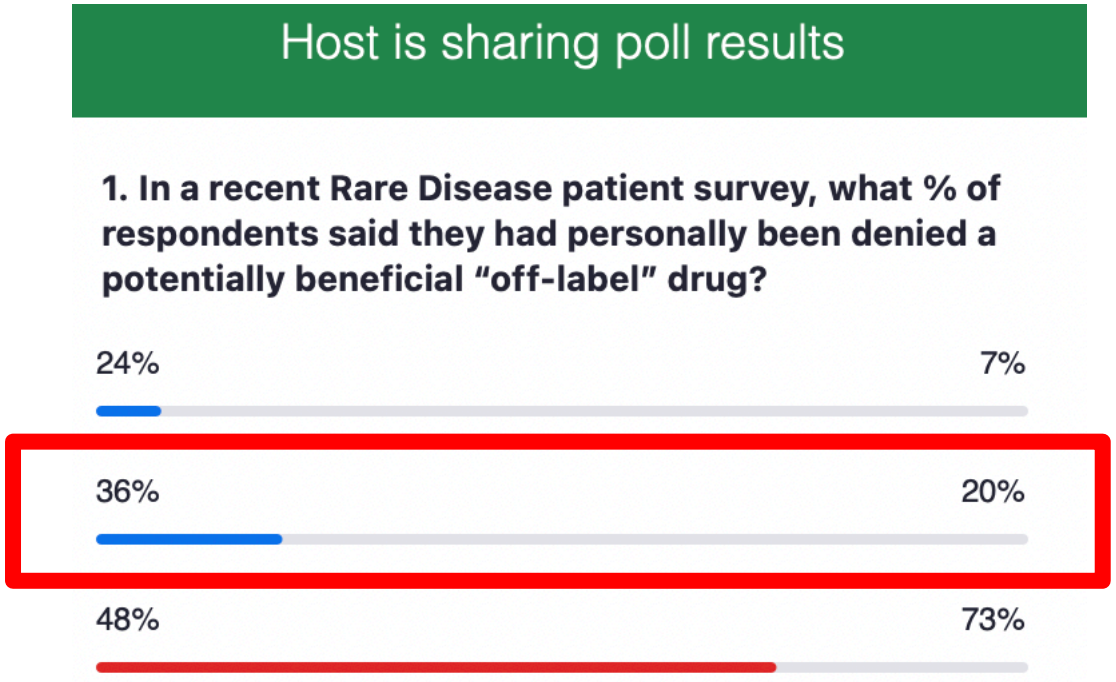
In a recent Rare Disease patient survey, what % of respondents said rare disease patients, in general, are denied or delayed in access to a prescribed drug through their Private Drug Plan?



Canadian Organization for Rare Disorders

Question #3 - Results

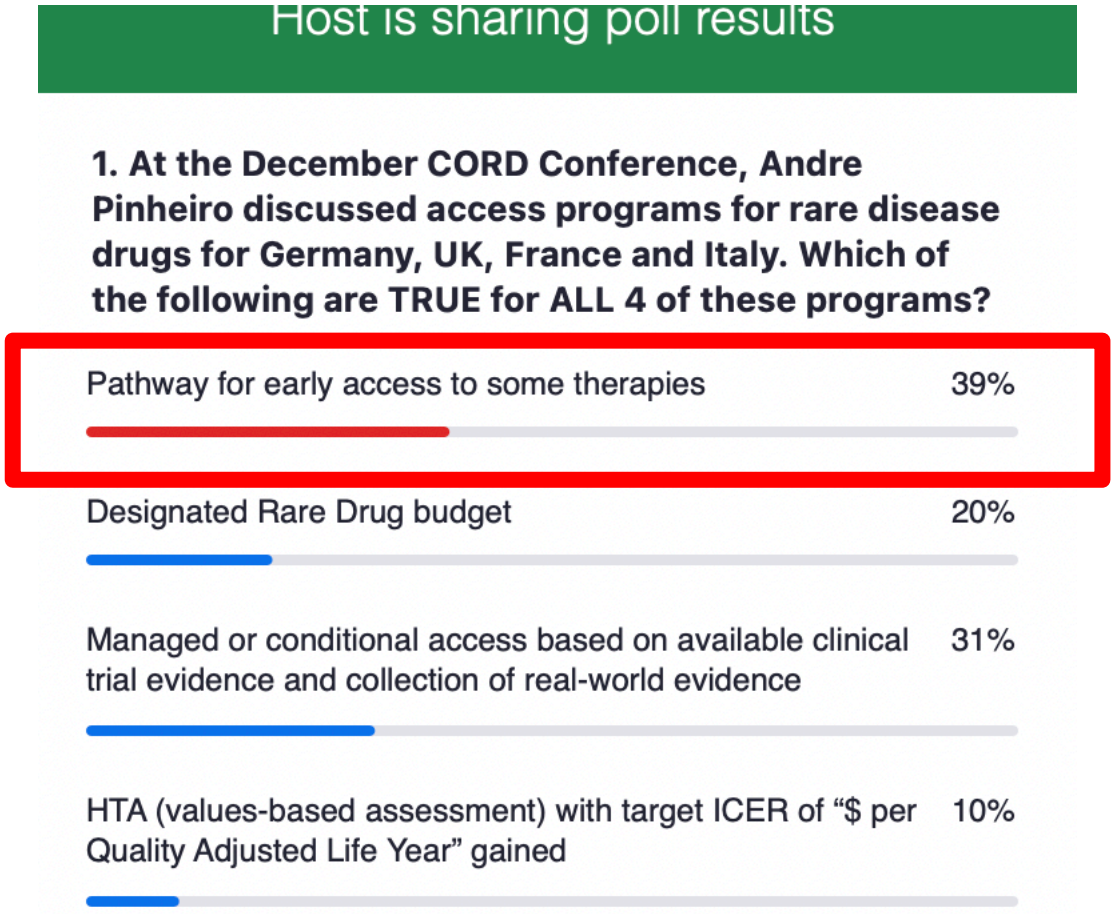
In a recent Rare Disease patient survey, what % of respondents said they had personally been denied a potentially beneficial “off-label” drug?



Canadian Organization for Rare Disorders

Question #4 - Results

At the December CORD Conference, Andre Pinheiro discussed access programs for rare disease drugs for Germany, UK, France and Italy. Which of the following are TRUE for ALL 4 of these programs?



Canadian Organization for Rare Disorders