



Canadian Organization
for Rare Disorders

“SORRY TO INTERRUPT SUMMER HOLIDAYS” Webinar Series

Webinar 2: Engaging Political Parties, Politicians,
and Policy Makers on Patient Needs
July 29, 2021



Welcome and Brief Overview

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

Four **BIG** Issues for update

- Health Canada's "What We Heard" report on Building a National Strategy for Drugs for Rare Diseases – they listened! **now...** to action as part of Canada's Rare Disease Strategy
- Continuing "Whack a Mole" with PMPRB: DOWN with implementation of new guidelines (3rd six-month hiatus); UP pops "out of the blue" pricing restrictions on grandfathered drugs – **now...** August 31 for input
- CADTH's new Advisory Panel for a pan-Canadian Prescription Drug List: **where's the rare?**
- SURPRISE! (Not). Federal election this fall. How do we align to align all political parties and political candidates to support "rare disease" and "rare drug" strategy (and safeguard the \$500 million annual commitment) **now...**

CORD's Mid-summer Super-panel and Town Hall!

Kathleen Monk, Earnscliffe Strategy Group

Geoff Turner, Bluesky Strategy Group

Roberta Kramchynsky, StrategyCorp

Moderators:

Durhane Wong-Rieger, CORD

Bill Dempster, 3Sixty Public Affairs



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THANK YOU FOR JOINING! OUR “SORRY TO INTERRUPT SUMMER HOLIDAYS” Webinar Series

*Tell your friends and colleagues who
missed our webinars to visit CORD's
YouTube and SlideShare Channels!*

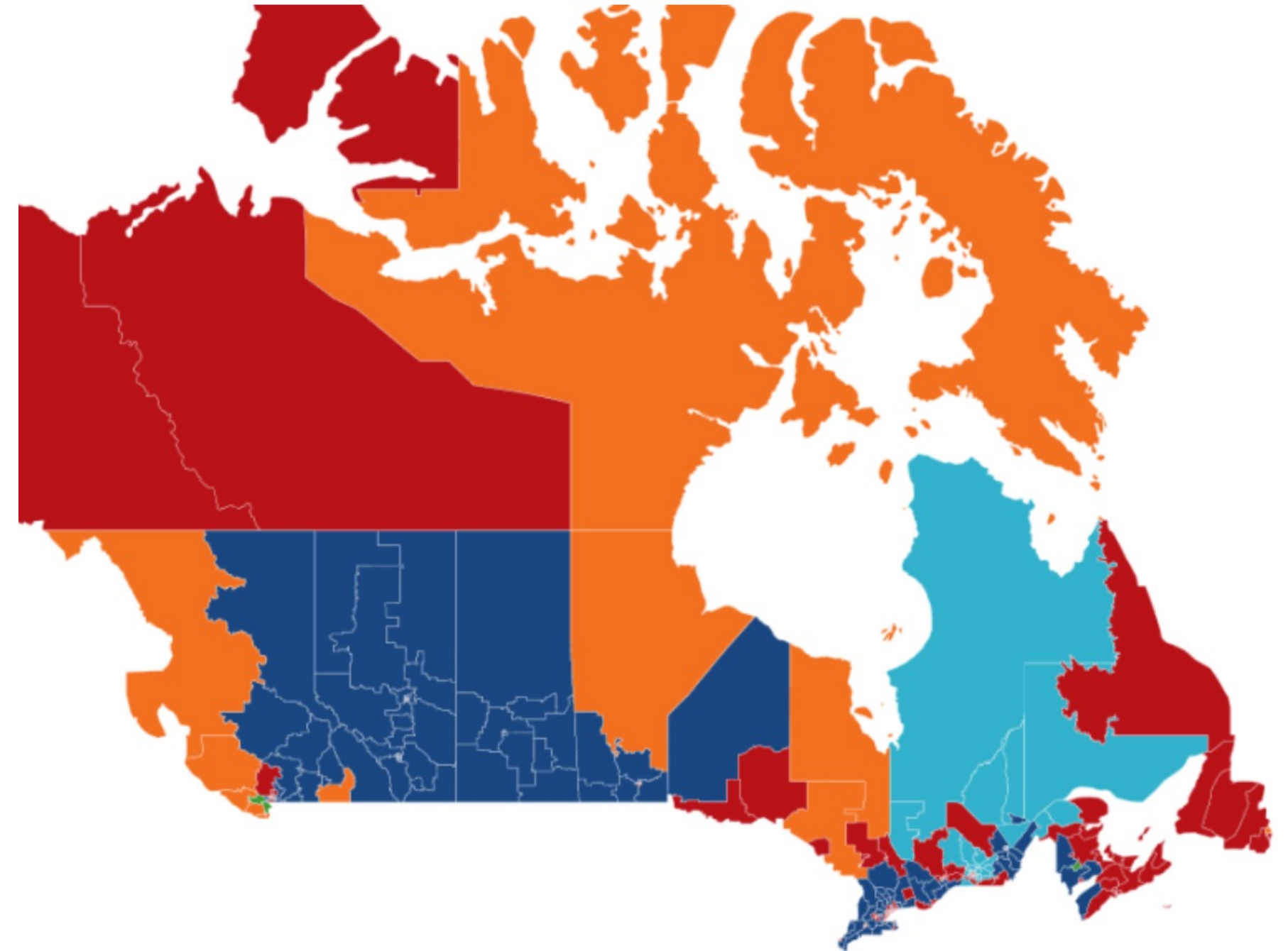
<https://www.youtube.com/user/CORDRareDisorders>

<https://www.slideshare.net/raredisorders>



Political situation

- Summer election call nearly a certainty despite PM's consistent denials
- Campaign teams, riding nominations, farewell speeches by exiting MPs, lawn signs ordered; COVID trends heading in the right direction
- Potential election timing: week of Aug 16/23 -> election Sept 27 or Oct 4
- Election calculus complicated & campaigns matter:
 - Liberals aim to make gains in BC and Ontario and hold current seats in Quebec
 - NDP / Jagmeet Singh's support rising which could split the left
 - Conservatives / O'Toole have higher "negatives" than other parties, but have not yet been in spotlight



Election issues / positions that could be relevant



**Justin
Trudeau**

**Erin
O'Toole**

**Yves-François
Blanchet**

**Jagmeet
Singh**

**Annamie
Paul**

- National Pharmacare
- Canada Drug Agency
- Rare Diseases Drug Strategy (\$500m/yr)

- Rare Diseases Treatments (\$500M/yr provinces-2019)
- Reform PMPRB

- Boost Canada Health Transfer

- “New Deal” that includes pharmacare

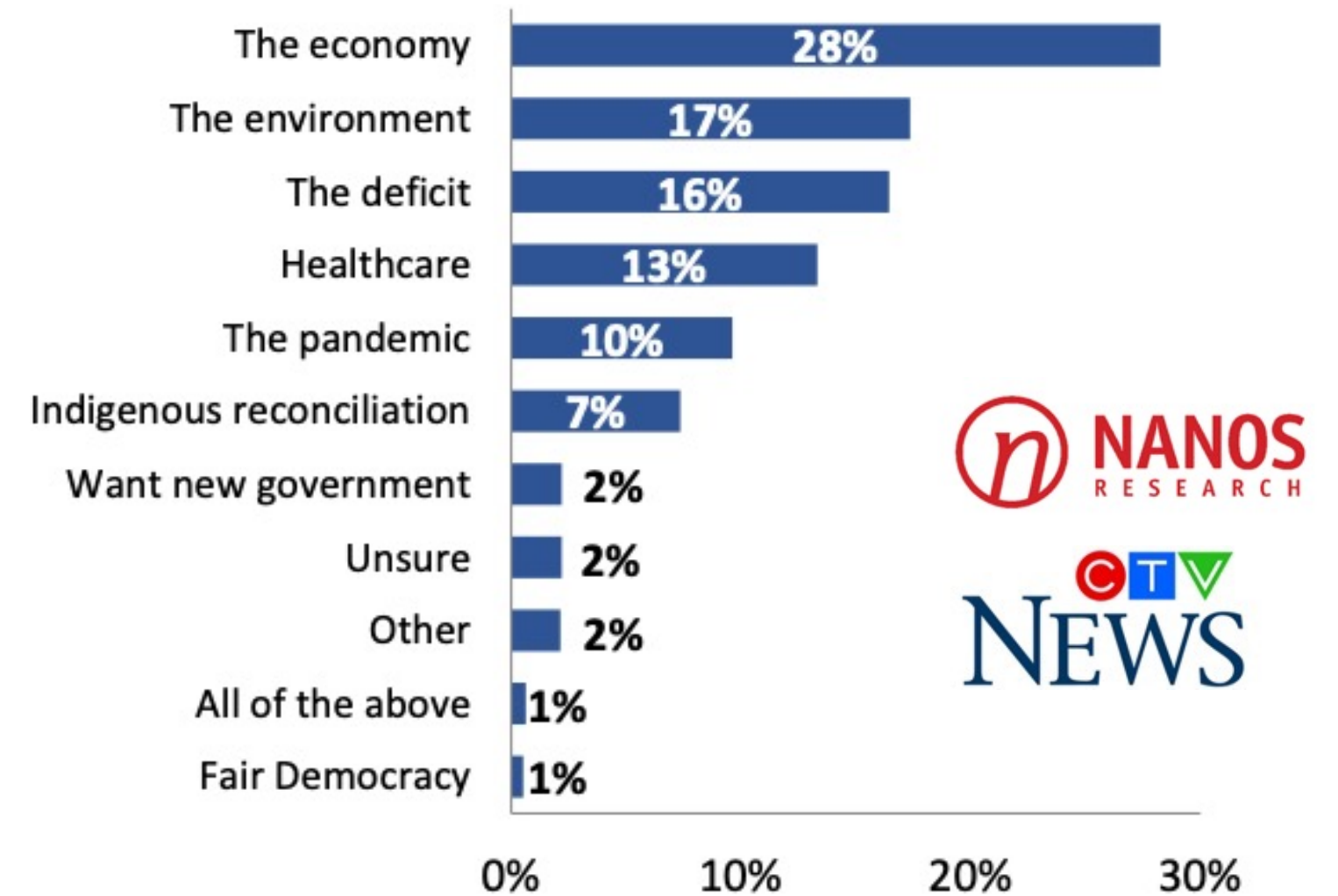
- National Pharmacare - basic formulary (2019)

What will the ballot box issue be?

- COVID pandemic response?
- Economic recovery?
- Deficits?
- Affordability (housing, gas, food, pharmacare, child care etc.)?
- Environment?



Most important policy that will influence vote



QUESTION: What will be the most important policy issue that will influence your vote if a federal election happens this coming Fall? [RANDOMIZE]

Source (graph): Nanos – National survey released July 2021. Nanos Research, RDD dual frame hybrid telephone and online random survey, June 30th to July 5th, 2021, n=1051, accurate 3.1 percentage points plus or minus, 19 times out of 20.

How to translate CORD's key asks into a high-impact election plan?

Jumpstart Canada's Rare Disease Drug Policy (2021)

1. Patient Empowerment
2. Canadian Rare Drug Agency
3. R&D incentives
4. Speed access to treatment
5. Regulatory barriers
6. Regulatory approvals process
7. Pathways for special cases
8. Multiple funding options
9. Managed Access Programs
10. Concurrent HC/HTA reviews
11. Real world evidence
12. Centres of clinical expertise

Canada's Rare Disease Strategy (2015)

1. Improving early detection and prevention
2. Providing timely, equitable and evidence-informed care
3. Enhancing community support
4. Providing sustainable access to promising therapies
5. Promoting innovative research

What CORD can propose for the federal election?

