Availability and Accessibility of Essential Drugs for Rare Disorders in Canada

Description

OPEN ACCESS

Availability and Accessibility of Essential Drugs for Rare Disorders in Canada

Nigel S B Rawson, PhD, Affiliated Scholar, Canadian Health Policy Institute

ABSTRACT

In 2021, the Rare Disease Treatment Access Working Group (RDTAWG) of the International Rare Diseases Research Consortium, a European Union funded organization, published a list of medicinal products that they considered to be essential for the treatment of rare conditions. This study assesses the availability and accessibility of the RDTAWG medicines in Canada by comparing whether the rare disorder medicines approved for marketing in the United States also had regulatory approval for the same indication in Canada, and whether those medicines are ultimately covered under the 10 provincial government drug plans and the federal Non-Insured Health Benefits plan for indigenous persons. Data available at the end of August 2021 were accessed from the relevant online drug formularies. Most (85%) of the medicines with regulatory approval in the United States were also approved for the same indication in Canada. However, only just over half were covered by either open or conditional access in government drug plans, with the proportion ranging from under 36% in Manitoba to two-thirds in New Brunswick. Approximately 20% of the medicines had open access in all the plans, whereas the proportion with conditional access ranged from 13% in Manitoba to 45% in Ontario and New Brunswick. The average rate of coverage for medicines for disorders with a prevalence of ?1 per 100,000 was only 28%, compared with 56% for disorders with a prevalence ranging from >1 case per 100,000 persons up to 1 case per 10,000 persons, and 60% for disorders with a prevalence of >1 case per 10,000 persons. Access to many medicines regarded by experts in the RDTAWG as essential for the welfare of individuals with rare disorders is inadequate to poor in Canada, especially for ultra-rare conditions. The federal Liberals and NDP are keen to introduce some type of national pharmacare. Any program developed by Canada’s governments must ensure that Canadians will have publicly funded access to all rare disorder medicines.

SUBMITTED: September 27, 2021. | **PUBLISHED**: October 13, 2021.

DISCLOSURES: None declared.

CITATION: Rawson, Nigel SB (2021). Availability and Accessibility of Essential Drugs for Rare Disorders in Canada. Canadian Health Policy, October 2021. ISSN 2562-9492 https://doi.org/10.54194/HFEB4050 www.canadianhealthpolicy.com