



**A BRIEF OF HEMOPHILIA AND
OTHER COAGULOPATHIES
SITUATION IN COLOMBIA 2020**



CUENTA DE ALTO COSTO

Fondo Colombiano de Enfermedades de Alto Costo

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Fondo Colombiano de Enfermedades de Alto Costo

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Situación de la hemofilia en Colombia 2020; Bogotá D.C. 2020.

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Chapter 1. Characterization of hemophilia and other coagulopathies new cases



Infographic content of chapter 1.

During the period there were reported

130
new cases of
coagulopathies

It represents a decrease of 23% compared with 2019, in which 169 new cases were reported.

Hemophilia new cases increased

compared
with
2019

On the other hand, von Willebrand disease and carriers new cases decreased by 23% and 67%, respectively.

42% of incident cases had:

Von Willebrand
disease
(VWD)

The second most common coagulopathy was hemophilia A (37%).

51% of new cases were women



Median age was 18 years (IQR: 4-32).

52% of new cases were affiliated to the third payer insurance



33% of new cases lived in the Central region, followed by the Caribbean region (22%).

The highest median age at diagnosis was observed in:

VWD
(20 years,
IQR: 12-35)

The lowest was observed in hemophilia A (2 years, IQR: 0-13).

52% of hemophilia A new cases had a severe form



Most of hemophilia B incident cases had mild disease (75%)



Chapter 2. Characterization of hemophilia and other coagulopathies prevalent cases



Infographic content of chapter 2

By 2020, 4,606 people with hemophilia and other coagulopathies were reported to the national registry



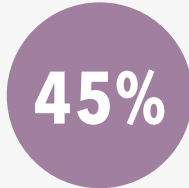
It means an increase of 6% compared with 2019.

There is an increase in the number of hemophilia A y B and VWD prevalent cases



Number of hemophilia carriers was lower than the reported in 2019.

The most frequent coagulopathy was hemophilia A with



45% of prevalent cases, followed by VWD (33%).

64% of prevalent cases were men



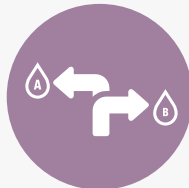
Median age of coagulopathies prevalent cases was 26 years (IQR: 16-42).

69% of prevalent cases were affiliated to the third payer insurance



30% of prevalent cases lived in the Central region, followed by Bogotá C.D. (25%).

36% of people with hemophilia A were between 10 and 24 years old



42% of people with hemophilia B were between 10 and 29 years old.

57% of people with hemophilia A were classified as severe



57% of people with hemophilia B were classified as moderate.



Chapter 3. Morbidity and mortality in people with hemophilia and other coagulopathies



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Infographic content of chapter 3.

Crude incidences of coagulopathies and hemophilia during the period were 2.63 and 1.13 new cases per 1,000,000 people, respectively

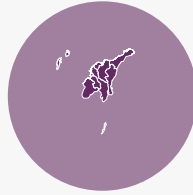
There was an increase in hemophilia A incidence while hemophilia B and coagulopathies incidences decreased compared with 2019.

Central and Bogotá C.D. regions had the highest age-standardized incidence rates of coagulopathies with:



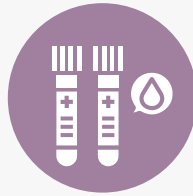
3.72 and 3.31 new cases per 1,000,000 people, respectively.

Age-standardized incidence rate of hemophilia was higher in people affiliated to the third payer than those with the state insurance:



1.23 vs.1.09 new cases per 1,000,000 affiliates, respectively.

Crude prevalence of coagulopathies, hemophilia A and hemophilia B were:



9.32, 4.20 and 0.92 cases per 100,000 people, respectively.

Bogotá C.D. and the Central region had the highest age-standardized prevalence with:



15.21 and 11.79 cases per 100,000 people, respectively.

Crude non-specific mortality rate in people with coagulopathies was:



0.24 deaths per 1,000,000 people.



Chapter 4: Treatment in people with hemophilia



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Infographic content of chapter 4.

56% (n=1,419) of people with hemophilia were under prophylaxis at the cutoff date



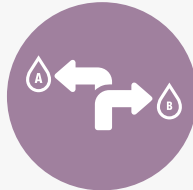
84% (n=1,192) of them had hemophilia A.

From people treated with prophylaxis, 84% (n=1,189) had severe hemophilia



~6% had high titre inhibitors.

In people with hemophilia A and B, standard half-life factors VIII and IX were:



The most frequently reported medications as part of prophylaxis.

From 1,419 people treated with prophylaxis, 1,155 had inhibitors test and from those:



12% (n=171) had some types of inhibitors, being more frequent in people with hemophilia A (91%, n=155).

98% of people with hemophilia and high titre inhibitors, receiving prophylaxis had:



Severe disease and 34% of those were treated with Emicizumab only or combined with factor VIII.

From people with hemophilia on demand at the cutoff date:



62% had mild hemophilia.

43% (n=17) of people with hemophilia treated with induction to immune tolerance received bypass agents



FEIBA was the most frequent (25%), followed by Novoseven (18%).



Chapter 5: Interdisciplinary management of people with hemophilia and other coagulopathies



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Infographic content of chapter 5.

In 93% of people with hemophilia:



Healthcare team was led by the hematologist.

Average number of clinical appointments per person.



Increased proportionally to the hemophilia severity.

Average of clinical appointments with hematologist went from:



2.15 in people with mild hemophilia to 7.25 in those with a severe form.

Average of clinical appointments with dentistry went from:



1.31 in people with mild hemophilia to 1.92 in those with a severe form.

Average of clinical appointments with psychology went from:



1.44 in people with mild hemophilia to 3.03 in those with a severe form.

Average of clinical appointments with nursing went from:



2.03 in people with mild hemophilia to 4.65 in those with a severe form.

Average of clinical appointments with physiotherapy went from:



1.82 in people with mild hemophilia to 5.54 in those with a severe form.



Chapter 6: Bleeding events in people with hemophilia



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Infographic content of chapter 6.

Hemarthrosis:

During the period, 27% of people with hemophilia had at least:



One bleeding event in the last year. From them, 26% were aged between 5 and 14 years.

76% of people with hemophilia A with clinically evident hemarthrosis had a severe form.



9% of people with hemophilia and hemarthrosis had high titre inhibitors.

Most people with hemarthrosis were treated with some type of prophylaxis (78%)



53% of hemarthrosis were traumatic which represents an annual bleeding rate of 1.46 episodes/person.

Extra-articular bleedings:

26% of people with hemophilia had some type of extra-articular bleeding during the period.



63% of those bleedings were observed in people under 25 years.

In people with hemophilia who had extra-articular bleedings:



63% had severe hemophilia.

Annual extra-articular bleeding rate from traumatic origin was 1.05 bleeds/person.



While annual extra-articular bleeding rate from spontaneous origin was 0.82 bleeds/person.



Chapter 7: Complications in people with hemophilia



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Infographic content of chapter 7.

Inhibitors presence:

Inhibitors incidence during the period was:



Hemophilia A -> 10%
Hemophilia B -> 4%

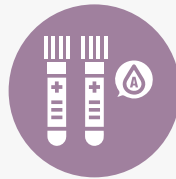
Compared with 2019, high titre inhibitors presence increased in both types of hemophilia.



53% of people with hemophilia A and high titre inhibitors were treated with secondary or tertiary prophylaxis.

Hemophilic chronic arthropathy

Presence of hemophilic chronic arthropathy was reported in 38% of people with hemophilia.



From those, 84% had hemophilia A.

52% of people with hemophilic chronic arthropathy:



Were in productive age groups (20-39 years).

Other complications

3% of people with hemophilia had history of hepatitis C virus infection.



4% had concomitant infections.

Complications such as pseudotumors, fractures or anaphylaxis were reported in less than 1%.



The most frequent disability was related with the mobility of the limbs.



Chapter 8: Risk management indicators



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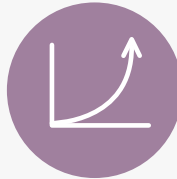
Infographic content of chapter 8.

General bleeding rates in people with hemophilia treated with prophylaxis with and without inhibitors decreased compared with 2019.



Improving the reporting process will allow to identify the real trend of this indicator.

Proportion of people treated with prophylaxis with hemophilic chronic arthropathy:



Slightly increased compared with 2019, going from 60% to 61%.

48% of people with hemophilia was managed by a multidisciplinary team. Despite there was an increase in relation with 2019:



This indicator was classified in the lower level of compliance.

Annual average of clinical appointments with hematology was 7.23 in people with severe hemophilia.



In people with mild/moderate hemophilia was 3.30. This indicator had a slight decrease compared with 2019.

Annual average of clinical appointments with dentistry was 1.91 in people with severe hemophilia.



In people with mild/moderate hemophilia was 1.51. This indicator increased compared with 2019.

Inhibitors incidence in people with moderate/severe disease was 13% and 6% in hemophilia A and B, respectively.



Compared with 2019, this indicator decreased in people with hemophilia A, while had a slight increase in people with hemophilia B.



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