

A BRIEF OF THE **HEMOPHILIA** AND OTHER COAGULOPATHIES SITUATION IN COLOMBIA 2022



Fondo Colombiano de
Enfermedades de Alto Costo

**A brief of the hemophilia and other coagulopathies situation
in Colombia 2022**



CUENTA DE ALTO COSTO
Fondo Colombiano de Enfermedades de Alto Costo

A brief of the hemophilia and other coagulopathies situation in Colombia 2022

Colombian High-Cost Diseases Fund
Cuenta de Alto Costo (CAC)

Annual periodicity

Bogotá, C. D., Colombia, may 2023

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Suggested citation: Cuenta de Alto Costo (CAC), Fondo Colombiano de Enfermedades de Alto Costo.
A brief of the hemophilia and other coagulopathies situation in Colombia 2022; Bogotá, C. D., Colombia 2023.

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The full textbook in Spanish of the situation of hemophilia and other coagulopathies in Colombia is available [HERE](#)



Characterization of **hemophilia** and other coagulopathies new cases

Chapter 1

at a glance

Characterization of hemophilia and other coagulopathies new cases

Period: February 1st, 2021 to January 31st, 2022

There were

172 new cases

with any coagulopathy;

34.88% of them had hemophilia, 9.30% were carriers, and 48.26% had von Willebrand disease.



Compared to 2021, there was a 27.41% increase in incident cases of coagulopathies and a 22.45% increase for hemophilia.



The median age at diagnosis for hemophilia A cases was 6 years (IQR: 1 - 26), while for hemophilia B was 10 years (IQR: 3 - 39).



The majority of the incident hemophilia cases (A+B) were between 0 - 4 years old.



The Central (35.42%) and the Caribbean (29.17%) regions reported most of the new hemophilia A cases.

58.33% of the incident hemophilia A cases were affiliated to state insurance.



Most of the new cases for both hemophilia A and B had mild forms of the disease. In most of the new cases of hemophilia, there was a family history of coagulopathies.





Characterization of **hemophilia** and other coagulopathies prevalent cases

Chapter 2

at a glance

Characterization of hemophilia and other coagulopathies prevalent cases

Period: February 1st, 2021 to January 31st, 2022

In 2022,

5,278 people

with any coagulopathy

were reported to the national registry; this means an increase of 8.53% compared to the previous year.



Hemophilia A was the most common coagulopathy, with 42.86% (n= 2,262) of the total cohort's patients, followed by von Willebrand disease with 35.39% (n= 1,868). Meanwhile, hemophilia B accounted for 9.61% of the total (n= 507).



The median age of the prevalent hemophilia A cases was 26 years (IQR: 15 - 40), while female carriers had a median age of 40 years (IQR: 28 - 49).



The Central region and Bogotá, C. D., registered the highest proportion of hemophilia cases.



Most of the prevalent cases of hemophilia were affiliated to the third-payer insurance (61.92%).

54.33% of the prevalent cases of hemophilia had a severe form of the disease, while the proportion for hemophilia B was 34.71%.



The most frequent presentation in women was the mild disease, while in men the severe form was the most common.





Morbidity and mortality in people with **hemophilia** and other coagulopathies

Chapter 3






at a glance

Morbidity and mortality in people with hemophilia and other coagulopathies

Period: February 1st, 2021 to January 31st, 2022

The crude incidence rate of coagulopathies was **3.37 new cases per million.**

For hemophilia A and B was 0.94 and 0.24, respectively.

-  Compared to the previous year, the crude incidence rate increased by 25.74% for coagulopathies, as well as an upward trend in this measure for hemophilia.
-  The Central and Pacific regions had the highest age-standardized incidence rates with 6.10 and 3.18 new cases per 1,000,000 people, respectively.
-  The crude prevalence of coagulopathies increased compared to the previous period and has historically maintained this upward trend.
-  Bogotá, C. D., and the Central region had the highest age-standardized prevalence rates of coagulopathies, with 15.64 and 13.19 cases per 100,000 people, respectively.
-  The third-payer insurance had the highest prevalence of hemophilia and other coagulopathies.

The crude all-cause **mortality rate of coagulopathies** was **0.45 per 1,000,000 people.**



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Treatment in people with hemophilia







Chapter 4

at a glance


Treatment in people with hemophilia

Period: February 1st, 2021 to January 31st, 2022

59.70% (n= 1,653)
of the total prevalent hemophilia cases
were negative for inhibitors.

-  Of the patients with hemophilia without inhibitors with on-demand treatment, 41.27% were treated with clotting factor concentrates.
-  Of the people with hemophilia and no inhibitors on prophylaxis, 85.54% (n= 958) had severe disease.
-  Among the people with hemophilia without inhibitors on prophylaxis, standard half-life recombinant factor VII and plasma-derived factor IX were the medications with the highest frequency of use.
-  In patients with hemophilia A without inhibitors on prophylaxis, 7.23% received extended half-life recombinant FVIII.
-  2.04% (n= 19) of patients of hemophilia A without inhibitors on prophylaxis received non-replacement therapy with Emicizumab in monotherapy or in combination.
-  34.78% of patients with hemophilia with inhibitors with on-demand treatment were treated with clotting factor concentrates.

Of the patients with high-titer inhibitors (n= 88), 84.09% (n= 74) were on prophylaxis.

-  Of the patients who received ITI during the period, 100% had inhibitor follow-up.






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Interdisciplinary management of people with hemophilia









Chapter 5

at a glance

Interdisciplinary management of people with hemophilia

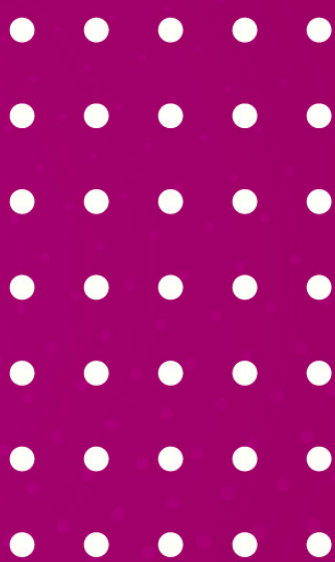
Period: February 1st, 2021 to January 31st, 2022

In **95.65%** (n= 2,504) of hemophilia cases, the hematologist was the specialist leading the medical management.

-  The main medical specialties involved in the control and follow-up of patients with hemophilia, with at least one consultation during the period, were hematology and orthopedics with 2,502 and 2,199 patients, respectively.
-  The average number of hematology consultations was 2.94 in mild hemophilia and 8.44 in severe forms.
-  4.27% (n= 112) of patients with hemophilia did not receive care from hematology, orthopedics, dentistry, psychology, or social work during the period, mainly due to refusal of care.
-  Around 80% of people with hemophilia were assessed by nursing and physiotherapy professionals.
-  Among the patients with hemophilic arthropathy, 91.89% (n= 873) received at least one orthopedic consultation during the period.
-  Compared to the previous period, the average number of healthcare appointments increased for all health disciplines except nursing.

The proportion of patients evaluated by a multidisciplinary team increased by 17% compared to the previous period.





Bleeding events in people with hemophilia



Chapter 6

at a glance

Bleeding events in people with hemophilia





Period: February 1st, 2021 to January 31st, 2022

Hemarthrosis




Of all patients with hemophilia,

76.17% (n= 1,994)

had no hemarthrosis during the period.

-  3.17% (n= 83) cases were spontaneous, 13.67% (n= 358) traumatic, and 2.75% a combination of both.
-  73.88% (n= 379) of people with hemarthrosis had severe hemophilia.
-  29.07% (n= 418) of patients on prophylaxis and 8,62% (n= 91) of those on-demand treatment had hemarthrosis, respectively.
-  Of the total of patients with high-titer inhibitors, 27.27% (n= 24) had at least one episode of hemarthrosis during the follow-up period.

Extra-articular bleeding

-  21.54% (n= 564) of patients with hemophilia had some type of extra-articular bleeding during the period.
-  In people with hemophilia with extra-articular bleeding, 55.67% (n= 314) had severe disease.
-  The mean annual frequency of extra-articular bleeding was 1.14 episodes (SD \pm 0.05) of traumatic origin and 0.57 (SD \pm 0.05) spontaneous origin.

0.26% (n= 7)

of patients with hemophilia had central nervous system bleeding.





Complications in people with hemophilia



Chapter 7

at a glance

Complications in people with hemophilia

Period: February 1st, 2021 to January 31st, 2022

Inhibitors

Among all patients with hemophilia,

70.70% (n= 1,851)

had inhibitors measurement,

of which high-titer were reported in **3.36%** (n= 88) and low-titer in **4.16%** (n= 109).



In patients with mild and moderate hemophilia, 2.09% (n= 27) were positive for inhibitors, while in those with severe forms of the disease, it was 12.78% (n= 170).

Chronic Hemophilic Arthropathy



Of patients on prophylaxis, 60.92% (n= 876) had chronic hemophilic arthropathy, whereas, in those with on-demand treatment, 6.25% (n= 66) had this complication.

59.69% (n= 794)

of individuals with severe hemophilia

had chronic hemophilic arthropathy.

Other complications



3.93% (n= 103) of people with hemophilia reported a history of hepatitis C virus infection.



Complications such as pseudotumor and fractures occurred in 0.30% of cases (n= 8).

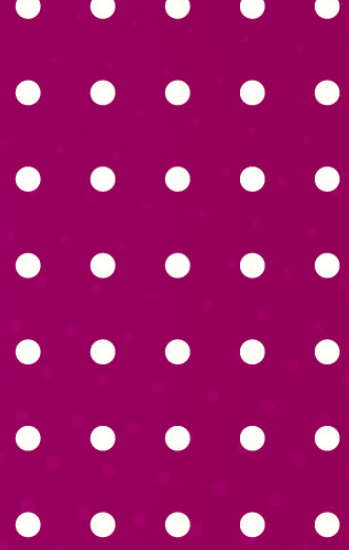


Anaphylaxis was reported in 0.08% (n= 2).

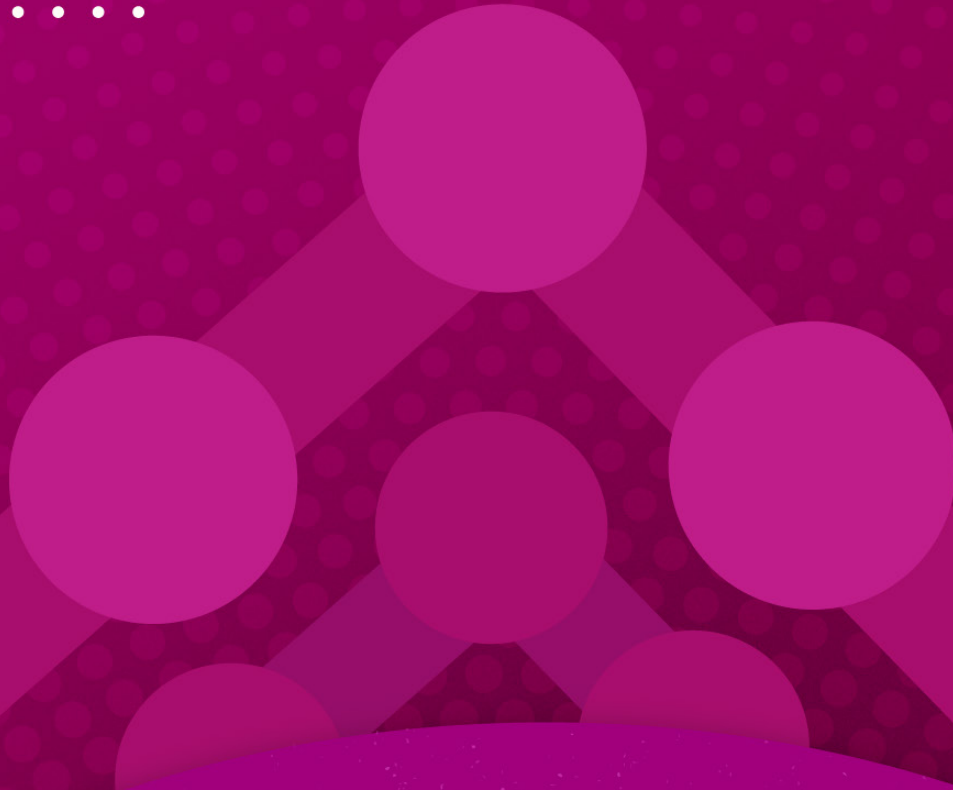
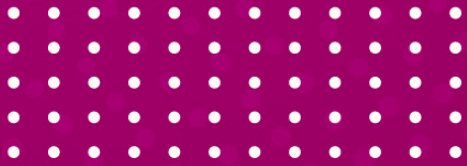


During the period, 2.02% (n= 53) of people with hemophilia reported some type of disability.





Risk management indicators








Chapter 8

at a glance

Risk management indicators

Period: February 1st, 2021 to January 31st, 2022

60.92% of people with hemophilia on prophylaxis during the period had chronic arthropathy.

-  General bleeding rates in people with hemophilia on prophylaxis decreased compared to 2021.
-  99.10% of people under 18 years with severe hemophilia and no inhibitors received prophylaxis during the period.
-  67.46% received care from an interdisciplinary team, showing an increasing trend since 2019.
-  The mean annual hematology consultations were 8.18 in people with severe hemophilia.
-  Adherence to integral healthcare was 52.45% in people with mild and moderate hemophilia on prophylaxis, whereas in cases with severe disease, it was lower (45.22%).

Of those on prophylaxis, **17.87%** self-infused independently, while 41.14% were infused with nursing assistance at home.





Von Willebrand disease








Chapter 9

at a glance

Von Willebrand disease

Period: February 1st, 2021 to January 31st, 2022

A total of
1,868 individuals
with VWD
were identified,
83 of them were incident cases.

-  Type 1 VWD was the most common subtype (45.78%) among prevalent cases.
-  Compared to the 2021 period, there was an increase of 38.33% in incident cases of VWD and 11.32% in prevalent cases.
-  The Central region had the highest proportion of incident cases (43.37%).
-  The majority of incident cases were diagnosed within the reproductive ages, with a median of 16 years (IQR: 9 - 28).
-  Among incident cases, 63.86% (n= 53) had a measurement of VWF:Ag, VWF:RCo and factor VIII clotting activity.

VWD: von Willebrand disease.

VWF:Ag: von Willebrand Factor Antigen.

VWF:RCo: von Willebrand Factor Ristocetin Cofactor.





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