

A brief of the

# HEMOPHILIA

and other coagulopathies  
situation in Colombia **2023**



Fondo Colombiano de  
Enfermedades de Alto Costo

**A brief of the hemophilia and other coagulopathies situation  
in Colombia 2023**



CUENTA DE ALTO COSTO  
Fondo Colombiano de Enfermedades de Alto Costo

# **A brief of the hemophilia and other coagulopathies situation in Colombia 2023**

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

Annual periodicity

Bogotá, C. D., Colombia, december 2023

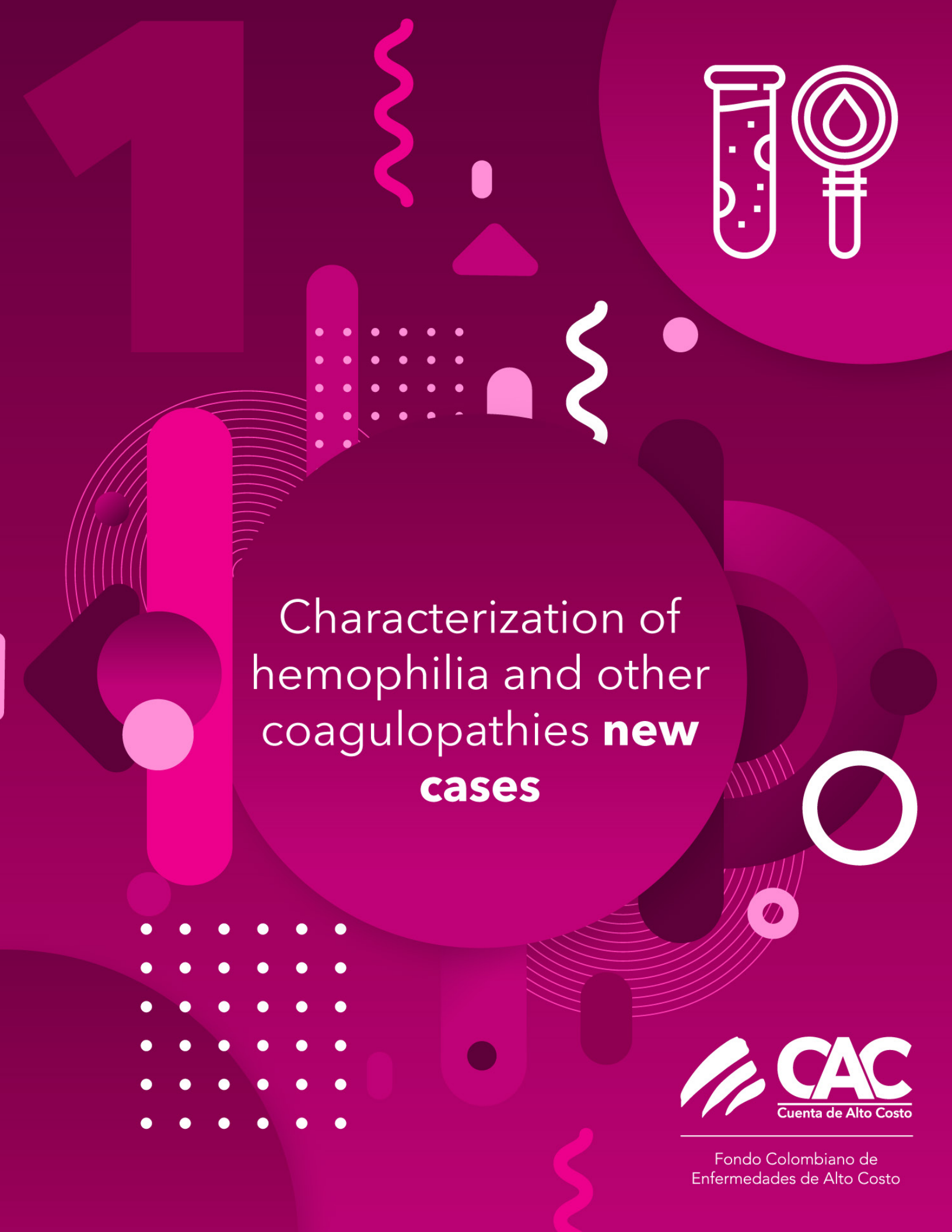
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The full textbook in Spanish of the situation of hemophilia and other coagulopathies in Colombia is available [HERE](#)




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

# Infographic summary

## Chapter 1 at a glance

Characterization of hemophilia and other coagulopathies new cases

**Period:** February 1<sup>st</sup>, 2022 to January 31<sup>st</sup>, 2023.



There were **191** new cases with any coagulopathy; 22.51% had hemophilia A, 3.14% hemophilia B and 61.78% had VWD.

Compared to 2022, incident cases of coagulopathies increased by **11.05%**, whereas new cases of hemophilia A and B decreased by 10.42% and 50.00%, respectively.



Out of the total coagulopathies new cases, 65.97% were women and the median age was 18 years.



58.14% of the incident hemophilia A cases belonged to the state insurance scheme while most new cases with hemophilia B (66.67%) were under third-payer insurance.



The Caribbean region grouped 23.26% of hemophilia A cases; meanwhile Bogotá, C.D. had 50.00% of hemophilia B cases.



The median age at diagnosis was 9, 4 and 18 years for patients with hemophilia A, hemophilia B and all coagulopathies, respectively.



Among men, 46.88% of hemophilia A and 60.00% of hemophilia B people presented the severe form of the disease.

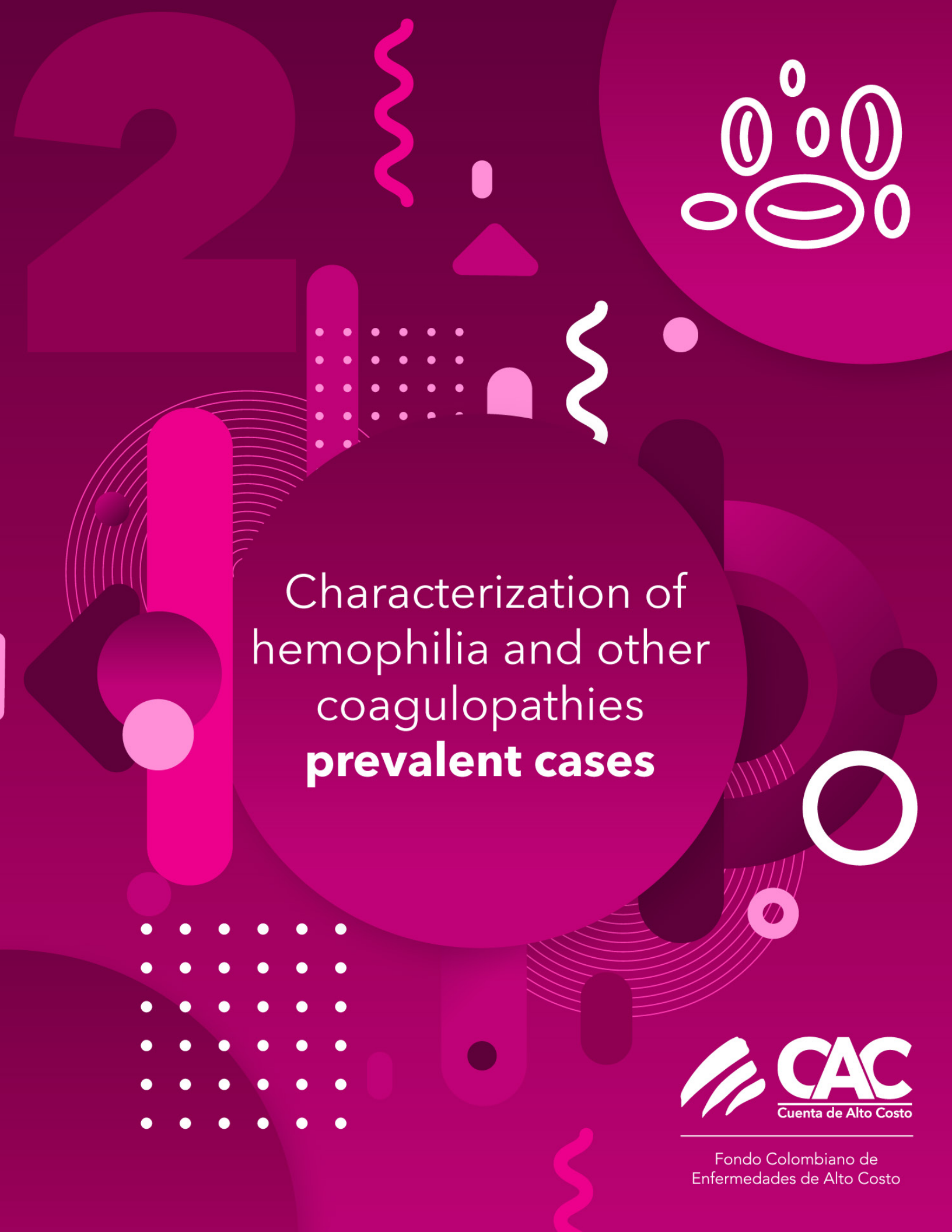


All incident cases of hemophilia among women had mild severity.

**53.49%** and **83.33%** new cases of **hemophilia A** and **hemophilia B**

had a family history of the disease.

**VWD:** von Willebrand disease.




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

# Infographic summary

## Chapter 2 at a glance

Characterization of hemophilia and other coagulopathies prevalent cases

**Period:** February 1<sup>st</sup>, 2022 to January 31<sup>st</sup>, 2023.



In 2023, **5,893** people with coagulopathies were reported to the national registry; it represents an increase of 11.65% compared to the previous year.

Hemophilia A was the most common coagulopathy, with **41.08%** of the total cohort's patients, followed by VWD at 38.03%, hemophilia B at 9.03% and carriers at 4.97%.



Most prevalent cases were men (57.15%) and the median age was 28 years.



The majority of prevalent hemophilia cases were between 15-19 years old.



The third-payer insurance accounted for the majority of prevalent cases of coagulopathies.



The Central region had the highest proportion of hemophilia A cases, while Bogotá, C. D., grouped most hemophilia B cases.



52.79% and 34.77% of prevalent hemophilia A and B cases had severe forms of the disease.



Among men, severe hemophilia was the most common form; whereas women presented mostly a mild disease.

**66.03%** of prevalent hemophilia cases had a family history of the disease.

VWD: von Willebrand disease.



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



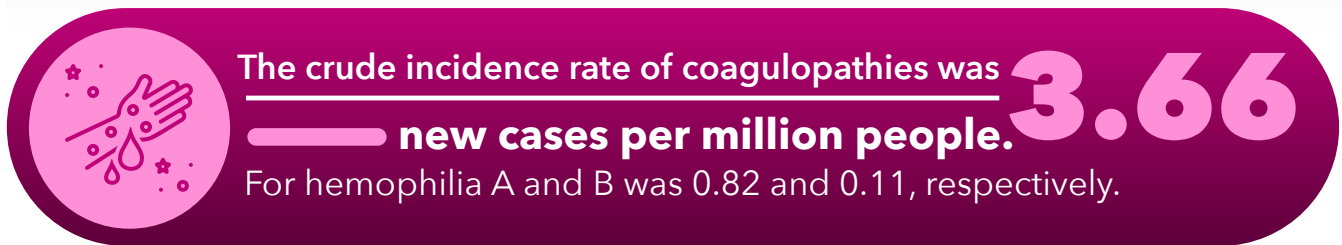
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# Infographic summary

## Chapter 3 at a glance

Morbidity and mortality in people with hemophilia and other coagulopathies

**Period:** February 1<sup>st</sup>, 2022 to January 31<sup>st</sup>, 2023.



Compared to the previous year, the **crude incidence rate of hemophilia A and B**

decreased by 12.77% and 54.17%, respectively.



Bogotá, C. D., and the state insurance had the highest SIR of both coagulopathies and hemophilia.



The crude prevalence rate of coagulopathies was 11.29 cases per 100,000 people, 9.19% higher than the previous year.



Bogotá, C. D., and the third-payer insurance scheme presented the highest SPR of coagulopathies, hemophilia A, and hemophilia B in men.

**24 all-cause deaths** were reported in 2023,

which represents a crude mortality rate of 0.46 cases per million people.

**SIR:** standardized incidence rate.  
**SPR:** standardized prevalence rate.



# Treatment in people with hemophilia



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# Infographic summary

## Chapter 4 at a glance

Treatment in people with hemophilia

Period: February 1<sup>st</sup>, 2022 to January 31<sup>st</sup>, 2023.



### Of the patients with hemophilia without inhibitors

receiving episodic treatment, 36.58% were treated with clotting factor concentrates.



Of the people with hemophilia without inhibitors on prophylaxis, 84.98% were severe cases.



Among patients with hemophilia without inhibitors on prophylaxis, standard half-life recombinant factors VIII and IX were the most frequently used treatments.



11.63% of patients with hemophilia A without inhibitors on prophylaxis, received extended half-life recombinant factor VIII.



Among patients with high-titer inhibitors, 87.65% were on prophylaxis, and 61.97% of those, received emicizumab.



100% of patients treated with ITI in the period, were tested for inhibitors.

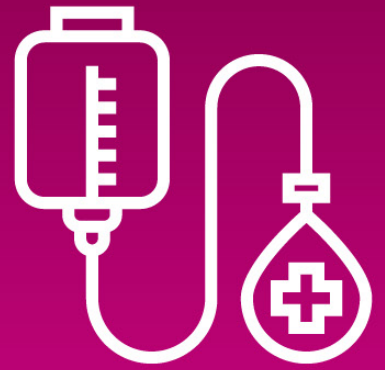


15.00% of patients with hemophilia with inhibitors on episodic treatment received clotting factor concentrates.

### 3.78% of patients with hemophilia A

without inhibitors on prophylaxis received non-replacement therapy with emicizumab in monotherapy or in combination.

ITI: immune tolerance induction.



# Interdisciplinary management of people with hemophilia



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# Infographic summary

## Chapter 5 at a glance

Interdisciplinary management of people with hemophilia

**Period:** February 1<sup>st</sup>, 2022 to January 31<sup>st</sup>, 2023.



## Hematology

was the specialty involved in the care of most patients, followed by psychology and social work.



The average number of consultations by the hematologist was 2.97 in patients with mild disease and 8.75 in those with severe disease.



4.54% of people with hemophilia did not receive interdisciplinary care. Of those, in the majority (90.77%) the cause was refusal of care.



76.03% of patients on prophylaxis and 67.07% of patients on episodic treatment had at least one consultation with the specialties of the interdisciplinary team.



69.19% of patients successfully accessed interdisciplinary care.



The average number of hematology and physical therapy consultations increased compared to the previous year.

**88.16%** of the patients with **chronic hemophilic arthropathy**

had at least one orthopedics consultation during the period.



**Bleeding events** in  
people with  
hemophilia



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# Infographic summary

## Chapter 6 at a glance

Bleeding events in people with hemophilia

**Period:** February 1<sup>st</sup>, 2022 to January 31<sup>st</sup>, 2023.



Of the patients with bleeding events during the period, 73.00% were on prophylaxis and 26.37% received episodic treatment.

### Hemarthrosis

**76.13%** of people with hemophilia had no hemarthrosis during the period.



4.05% of cases with hemarthrosis had spontaneous events, 12.46% traumatic, and 2.93% a combination of both.



76.66% of people with hemarthrosis had severe hemophilia.



30.01% of patients on prophylaxis and 7.09% of those on episodic treatment had hemarthrosis, respectively.



32.10% of people with high-titer inhibitors had at least one episode of hemarthrosis during the period.

### Extra-articular bleeding



22.19% of patients with hemophilia had some form of extra-articular bleeding during the period.



Among people with hemophilia and extra-articular bleeding, 59.75% had a severe form of the disease.



The median frequency of extra-articular bleeding was one annual event (IQR: 1-2) of traumatic origin and 0 events (IQR: 0-1) of spontaneous origin.

**0.42%** of patients with hemophilia had central nervous system bleeding.

IQR: interquartile range.



# Complications in people with hemophilia



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# Infographic summary

## Chapter 7 at a glance

Complications in people with hemophilia

**Period:** February 1<sup>st</sup>, 2022 to January 31<sup>st</sup>, 2023.

### Inhibitors



**72.37%** of patients with hemophilia

were tested for inhibitors. Among those, 2.83% had high-titer and 3.14% low-titer inhibitors.



Inhibitors were found in 1.27% of patients with mild and moderate hemophilia and 10.55% of those with severe disease.

### Chronic Hemophilic Arthropathy

**64.69%** of individuals with **severe hemophilia**

had chronic hemophilic arthropathy.



Of patients on prophylaxis, 65.61% had chronic hemophilic arthropathy, whereas, in those on episodic treatment, 9.59% had presented this complication.

### Other complications



3.42% of people with hemophilia reported a history of hepatitis C virus infection.



Complications such as pseudotumor and fractures occurred in 0.42% and 0.31% of cases, respectively.

**2.16%** of people with **hemophilia**

reported some disability, 74.19% had hemophilia A, and 82.26% had the severe form of the disease.



# Risk management **indicators**



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# Infographic summary

## Chapter 8 at a glance

Risk management indicators

Period: February 1<sup>st</sup>, 2022 to January 31<sup>st</sup>, 2023.



**96.88%** of patients aged <18 years with severe hemophilia without inhibitors received prophylaxis.

**68.65%** of people with hemophilia received interdisciplinary care.



Compared to the previous period, general bleeding rates in patients with inhibitors on prophylaxis decreased by 19.32%, whereas spontaneous bleeding rates increased by 7.32%.



In patients without inhibitors on prophylaxis, the articular bleeding rates decreased by 7.69%, and by 38.10% for the spontaneous bleeding cases, compared to the previous year.



65.59% of patients with hemophilia on prophylaxis have chronic hemophilic arthropathy.



The average number of hematology and odontology appointments was 8.57 and 1.91 in patients with severe hemophilia, respectively.



Self-infusion at home was present in 16.83% of the patients, while 43.18% received assistance from a nurse.



Compared to the previous year, adherence to integral care increased by 8.33% in people with mild or moderate hemophilia and by 1.68% in patients with severe hemophilia.

**4.47% and 1.34%** of patients with **hemofilia A and B** had high-titer inhibitors during the period, respectively.



# Von Willebrand disease



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# Infographic summary

## Chapter 9 at a glance

Von Willebrand disease

**Period:** February 1<sup>st</sup>, 2022 to January 31<sup>st</sup>, 2023.



The Central and Pacific regions had most new cases of VWD, with 23.73% each.



Among the incident cases, the median age at diagnosis was 19 years, and type I form was the most common (47.46%).

**2,241** prevalent VWD cases were reported,  
19.97% more than in the previous period.

**76.08%** of prevalent cases were **women,**  
with a median age of 28 years, and 72.74% had third-payer insurance.



Episodic treatment was used in 80.90% of all cases.



Tranexamic acid was the most common drug among prevalent cases (16.30%).

**VWD:** von Willebrand disease.



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