

# Annual Report 2020

published by  
the DHR office

Data exported on  
September 7, 2021

Paul-Ehrlich-Institut 

Bundesinstitut für Impfstoffe  
und biomedizinische Arzneimittel





The DHR office is located at the Paul-Ehrlich-Institut (PEI)

## Office



Dr. Christine Keipert  
(Head)



Dr. Heike Duda



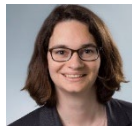
Birgit Haschberger



Janina Hesse



Olaf Henseler



Dr. Hanna Windecker

## Steering Committee

For the Patient Organisations

DHG

Björn Drebing  
Dr. Anna Griesheimer

IGH

Dr. Thomas Becker  
Christian Schepperle

For the medical society  
GTH

Prof. Dr. Karin Kurnik  
Prof. Dr. Andreas Tiede (Chair)

For the Federal Institute  
PEI

Dr. Anneliese Hilger (Vice chair)  
Dr. Christine Keipert

## Scientific Committee

Representatives of

Patient Organisations  
DHG, IGH

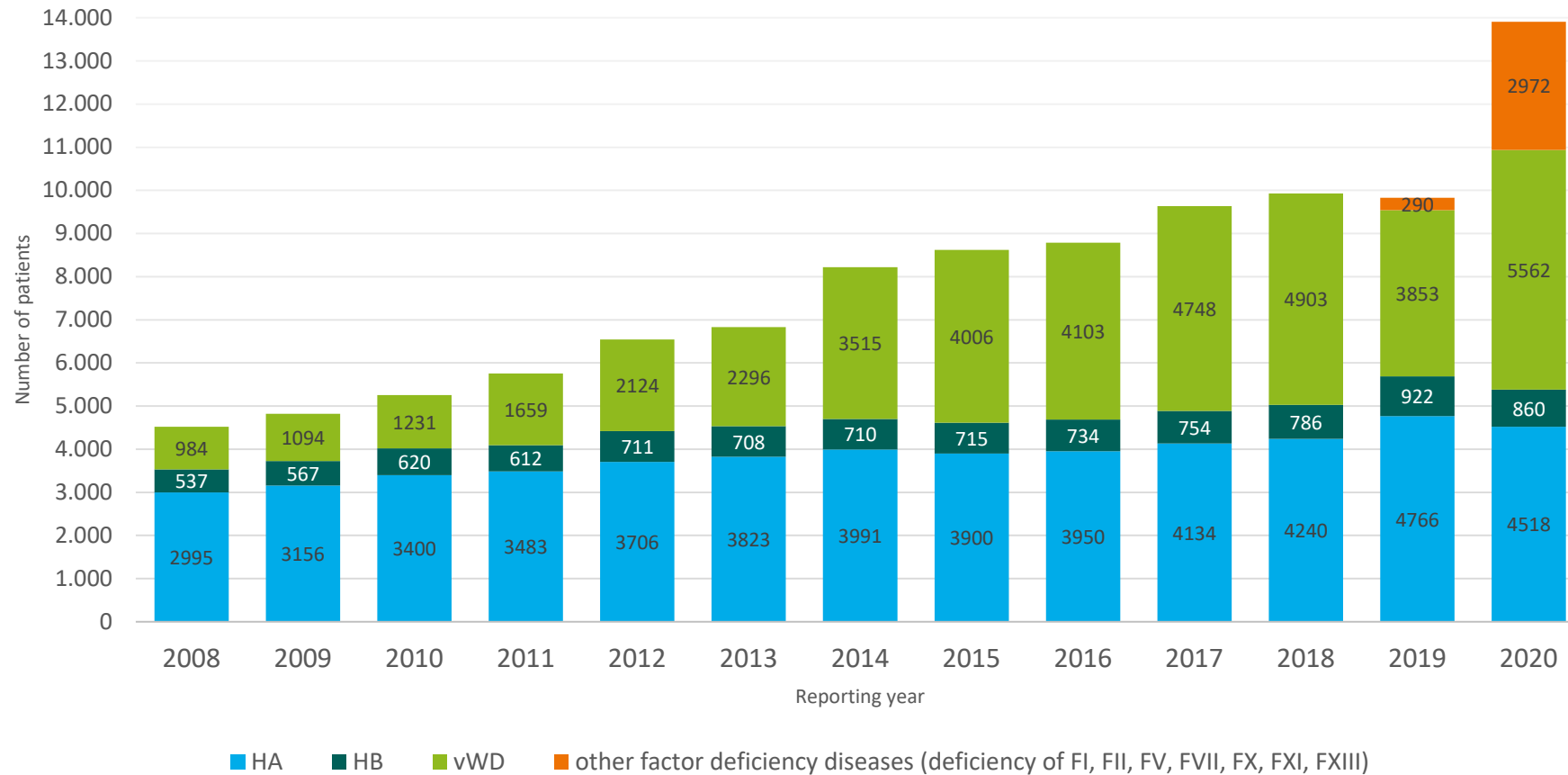
Medical Societies  
BDDH, DGTI, GTH

Pharmaceutical industry associations  
PPTA, VfA

National Association of Statutory health  
Insurance Funds  
GKV-Spitzenverband

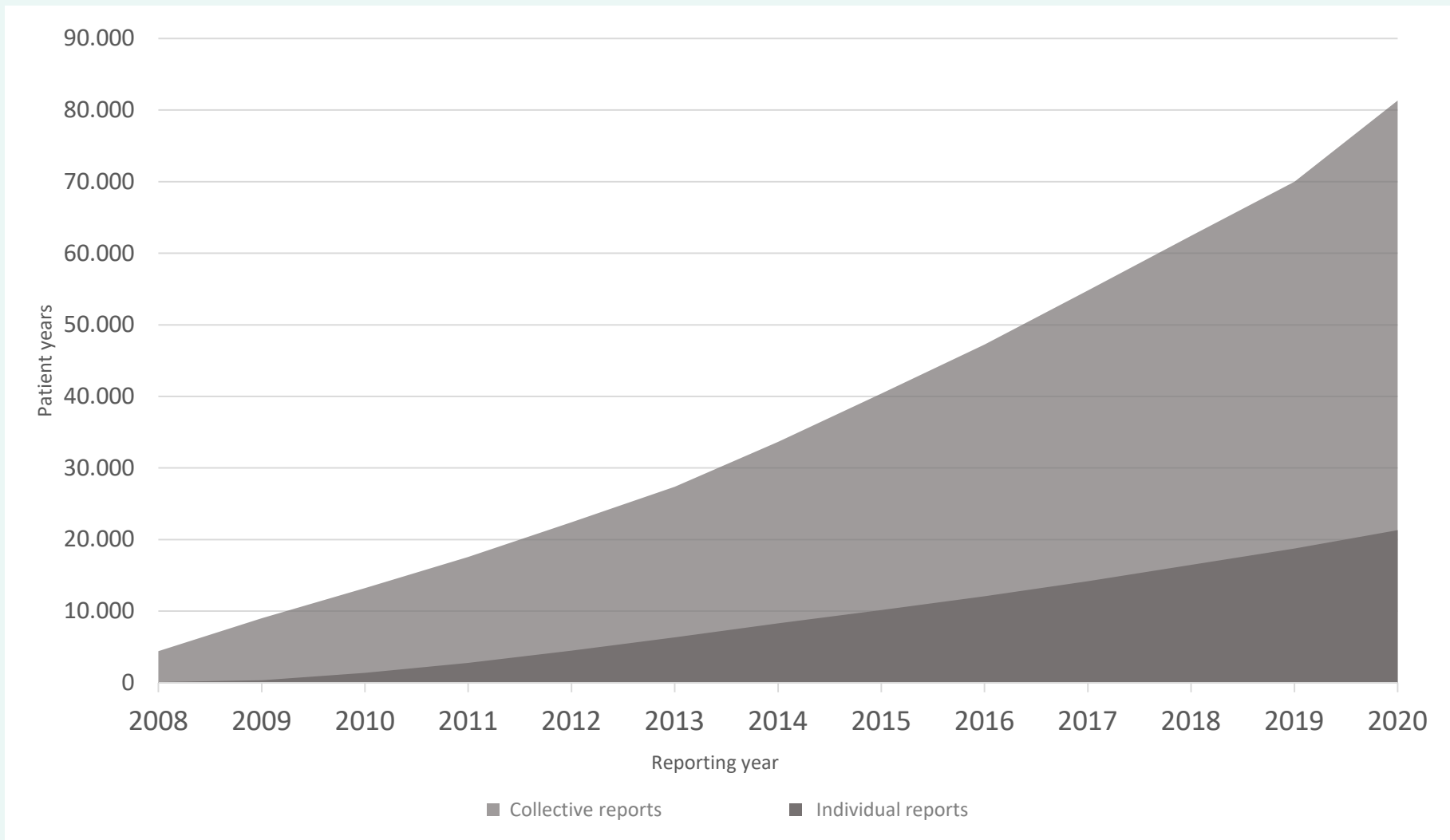
Private health insurer associations  
PKV

Healthcare provider associations  
DKG, KBV

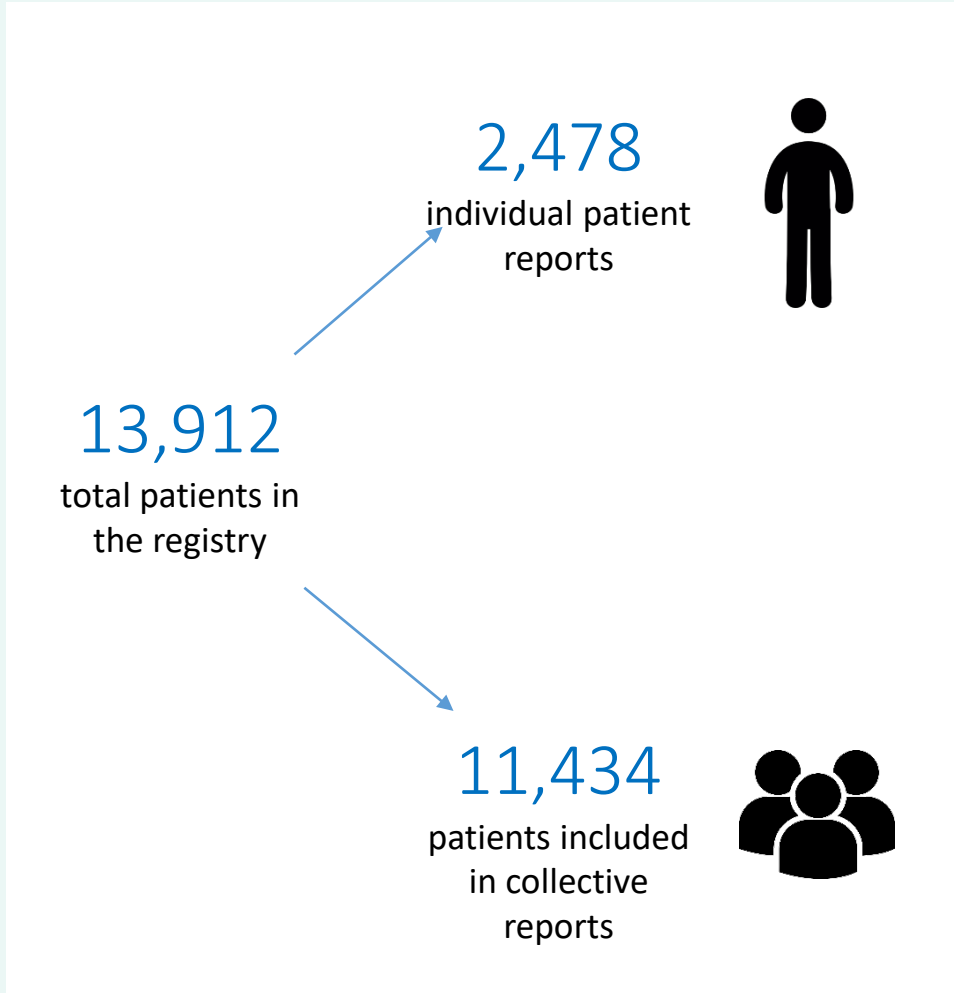


Since 2008, the DHR has been collecting specific data from individuals with blood coagulation disorders in Germany.

Since the expansion of the Transfusion Act in 2019, in addition to persons with haemophilia A (HA), haemophilia B (HB) and von Willebrand disease (vWD), individuals with other factor deficiency diseases must now also be included in individual or collective reports. The reported number of patients with rare factor deficiency diseases has since risen sharply.

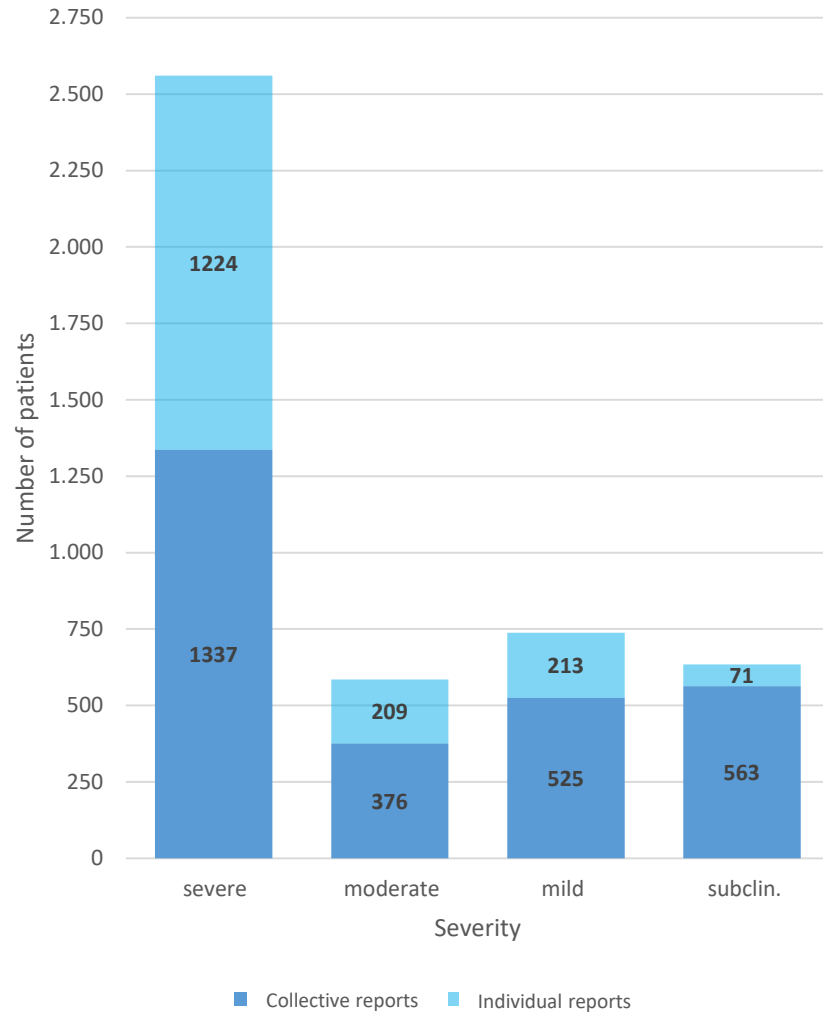


Since 2008, a total of 102,638 patient-years have been recorded in the DHR from all reported patients. A total of 81,320 patient-years were recorded in the collective report and 21,318 patient-years in individual reports.

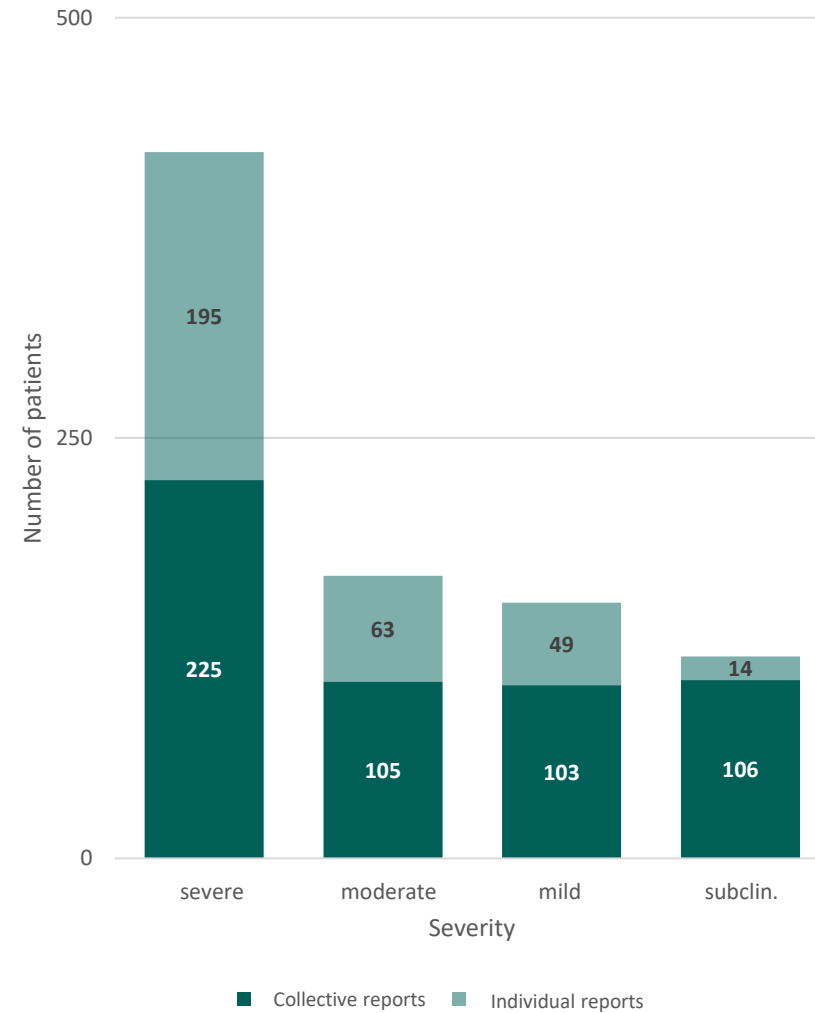


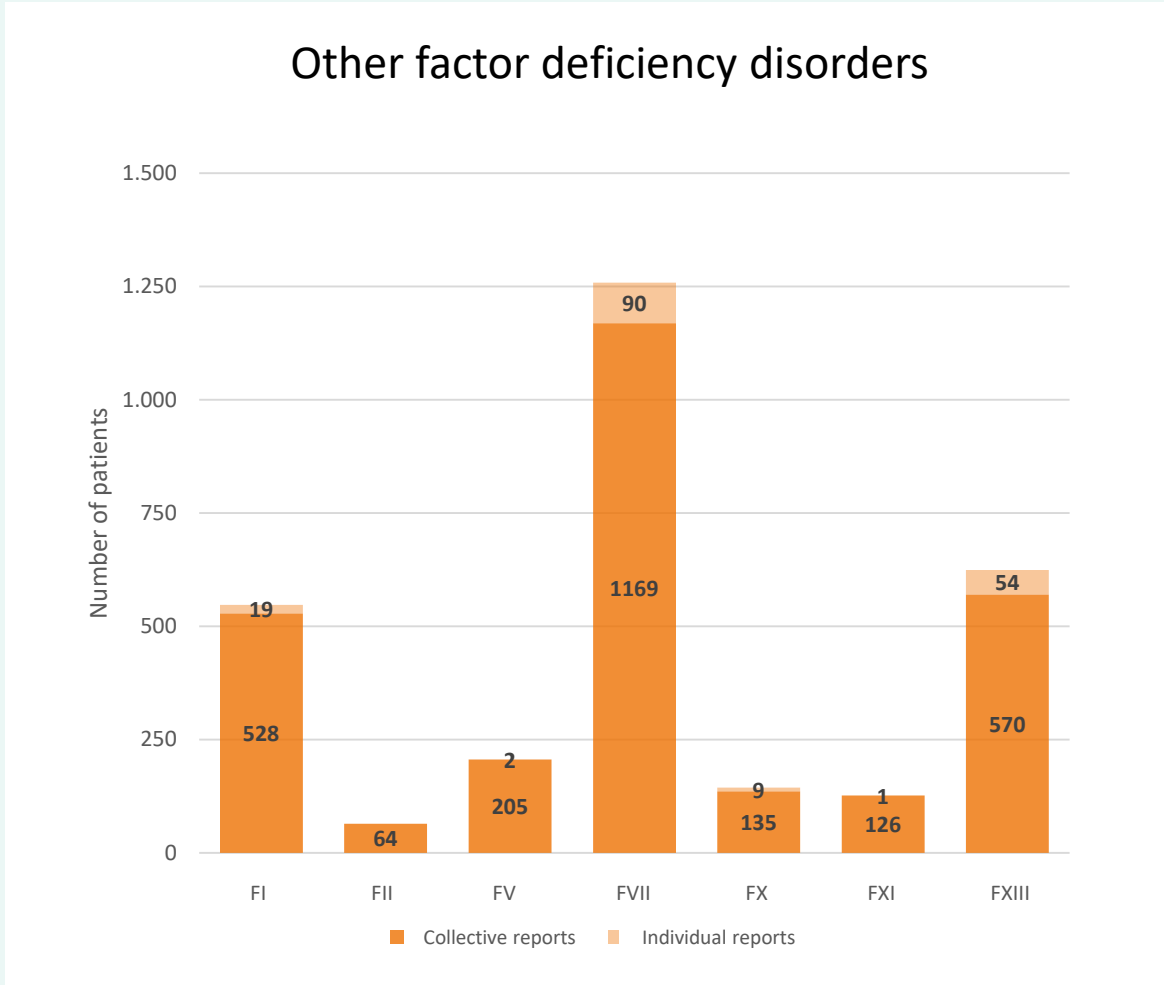
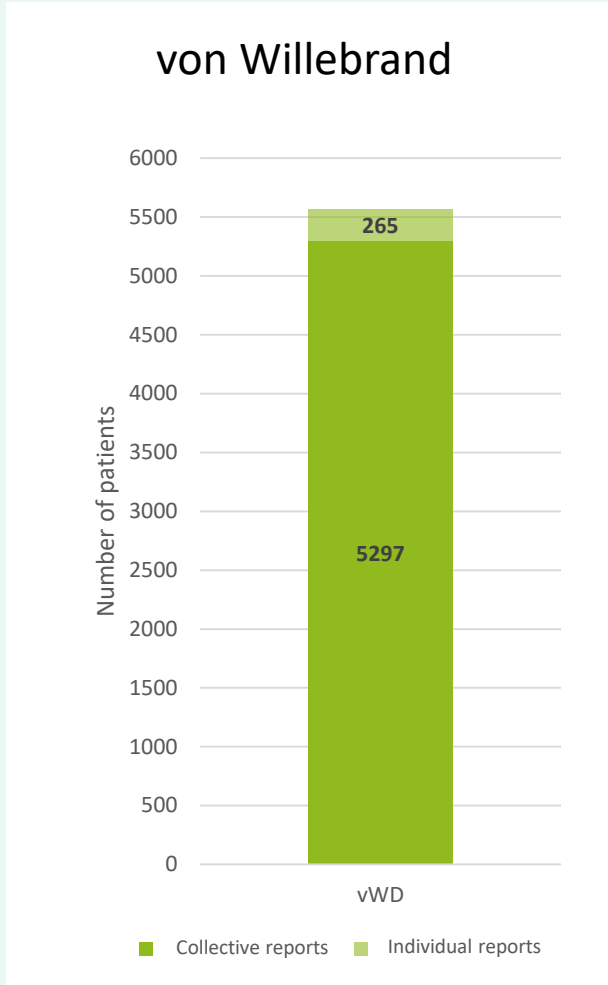
In 2020, 140 clinics, treatment centres and specialized medical practices reported data for a total of 13,912 people. 2,478 patients gave their consent to an individual report. This is 397 more patients than in 2019. 11,434 patients were recorded via collective reports, which corresponds to an increase of 4,961 patients.

### Haemophilia A



### Haemophilia B

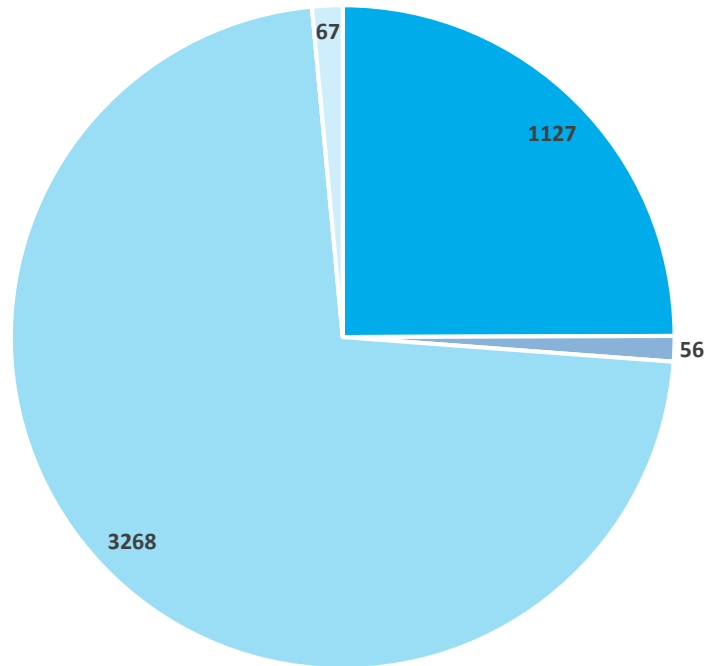




In 2020, a total of 5,562 people affected by von Willebrand's disease and 2,972 people affected by other factor deficiency diseases were reported to the dhr. 2020 is the first year in which there was an increase of these patients in the collective report. Only a small proportion of these patients require treatment with coagulation products.

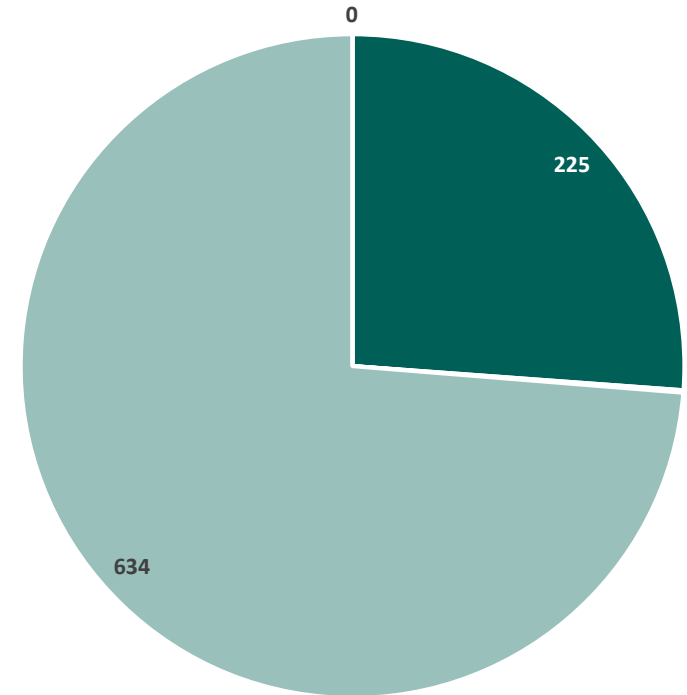


## Haemophilia A



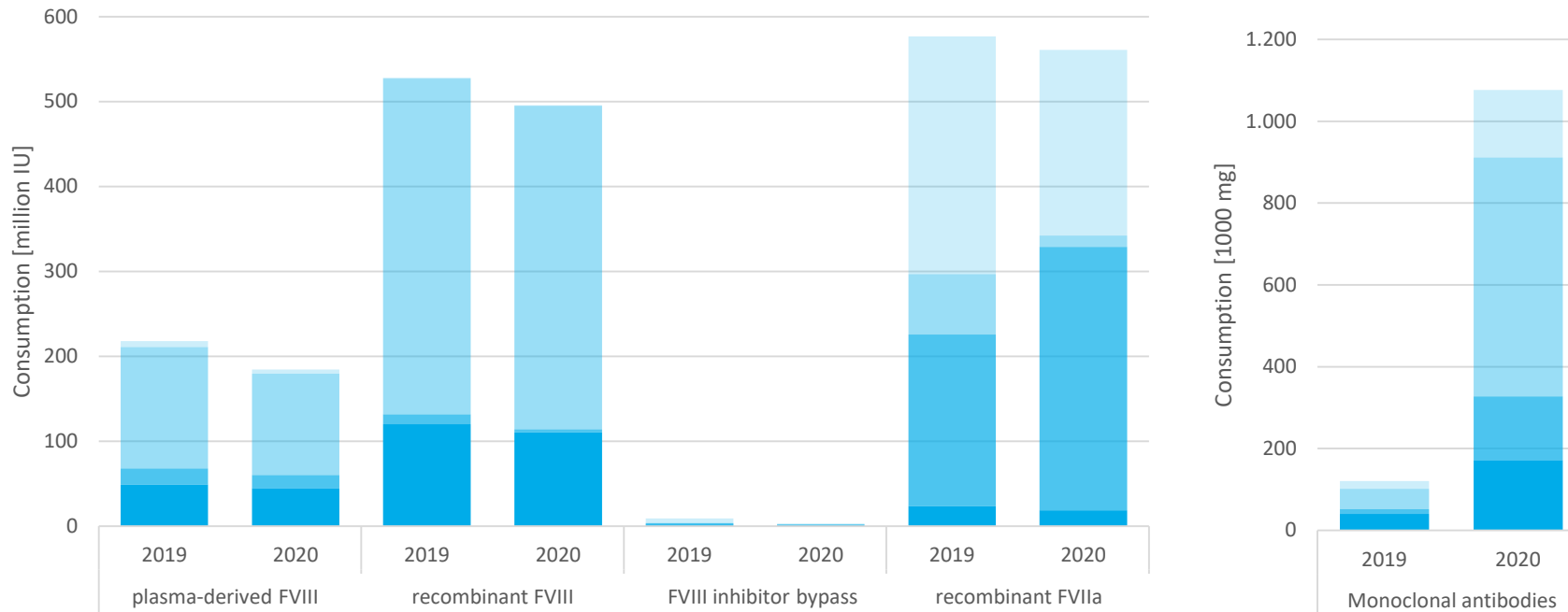
- Children/adolescents without inhibitors
- Children/adolescents with inhibitors
- Adults without inhibitors
- Adults with inhibitors

## Haemophilia B



- Children/adolescents without inhibitors
- Children/adolescents with inhibitors
- Adults without inhibitors
- Adults with inhibitors

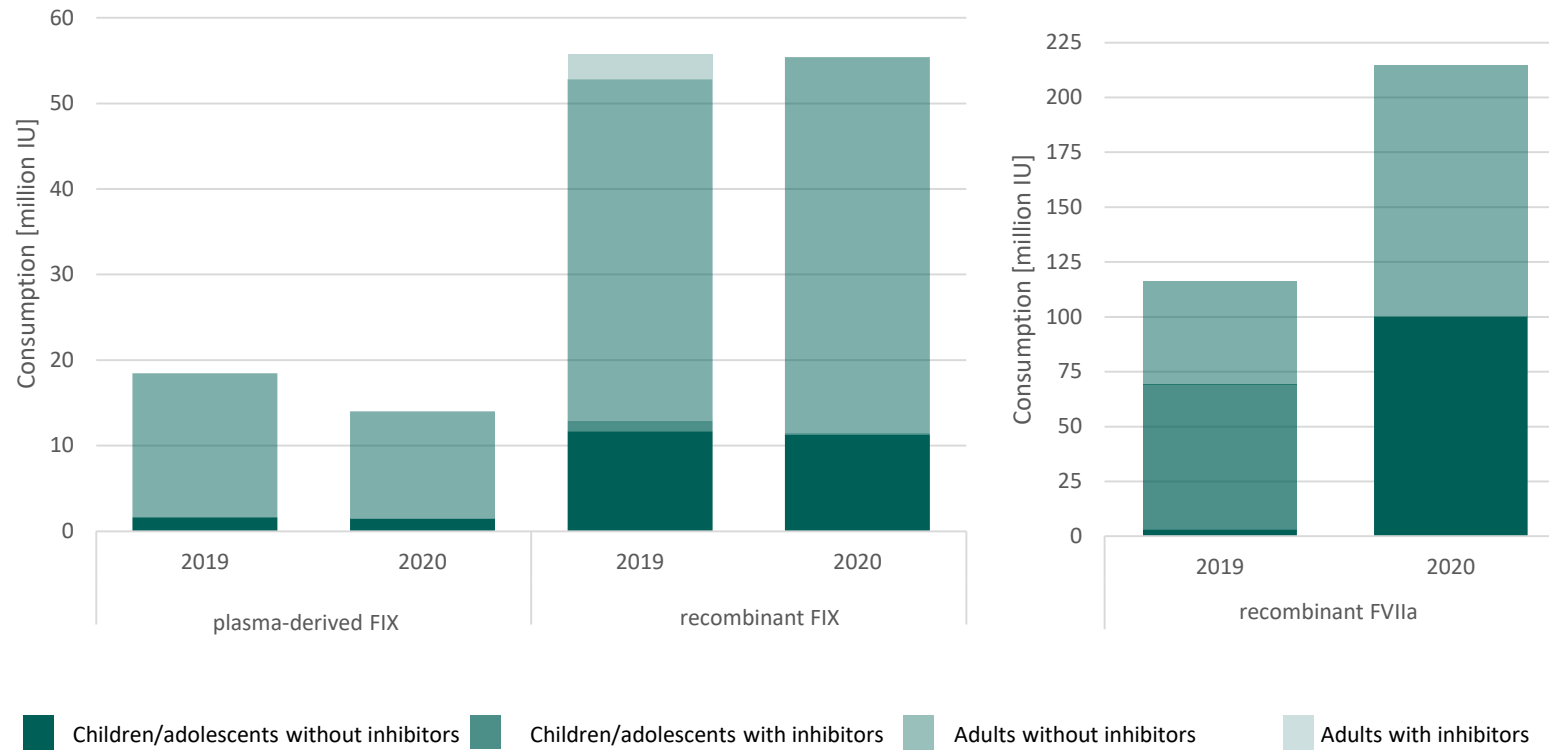
### Haemophilia A



■ Children/adolescents without inhibitors 
 ■ Children/adolescents with inhibitors 
 ■ Adults without inhibitors 
 ■ Adults with inhibitors

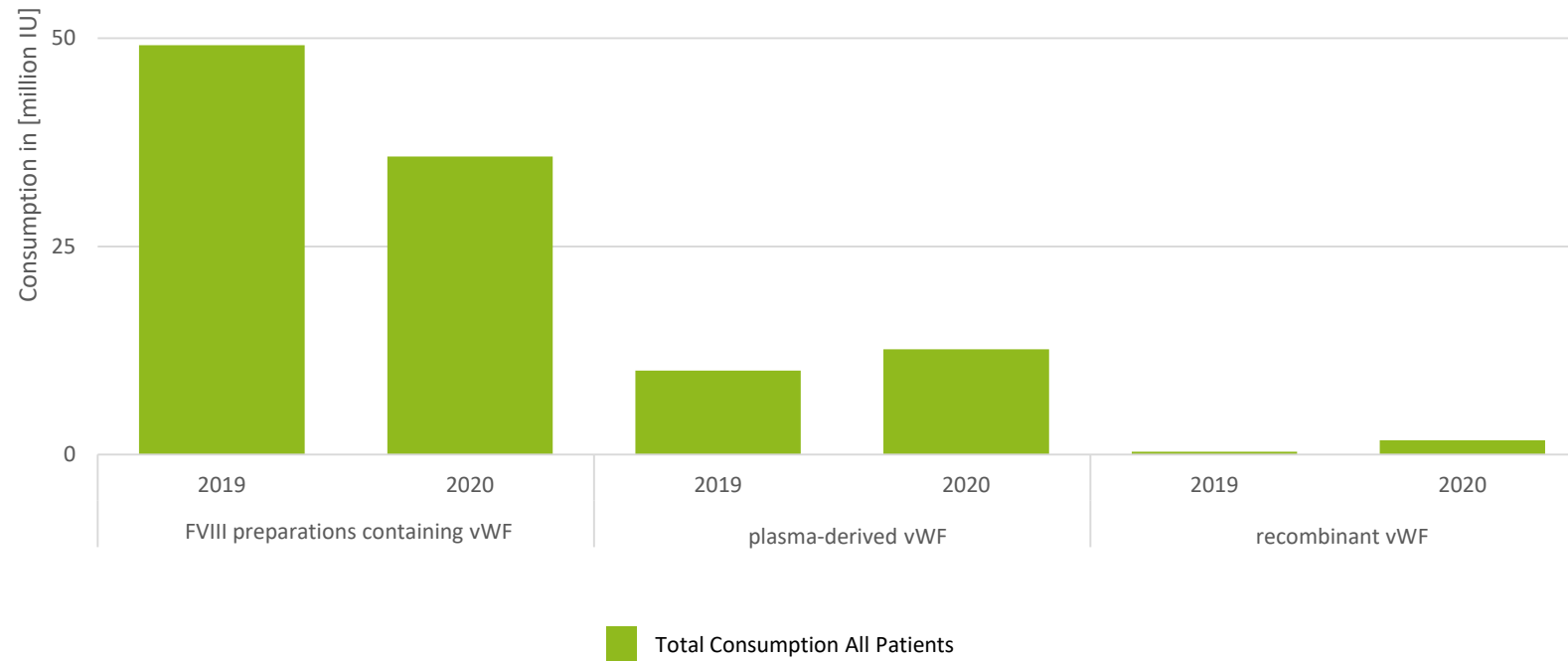
Haemophilia A patients Consumption 2020	Number [n]	patients that received treatment [n]	plasma-derived FVIII [IU]	recombinant FVIII [IU]	FVIII inhibitor bypass [IU]	recombinant FVIIa [IU]	monoclonal antibody [mg]
Children and adolescents without inhibitors	1,127	894	44,512,770	110,363,290	1,669,500	18,450,000	171,690
Children and adolescents with inhibitors	56	49	15,401,250	3,494,400	0	310,350,000	155,872
Adults without inhibitors	3,268	2,322	119,531,274	381,111,300	38,000	13,250,000	584,065
Adults with inhibitors	67	59	4,782,000	577,900	1,288,500	218,950,000	164,655
<b>Total</b>	<b>4,518</b>	<b>3,324</b>	<b>184,227,294</b>	<b>495,546,890</b>	<b>2,996,000</b>	<b>561,000,000</b>	<b>1,076,282</b>

## Haemophilia B

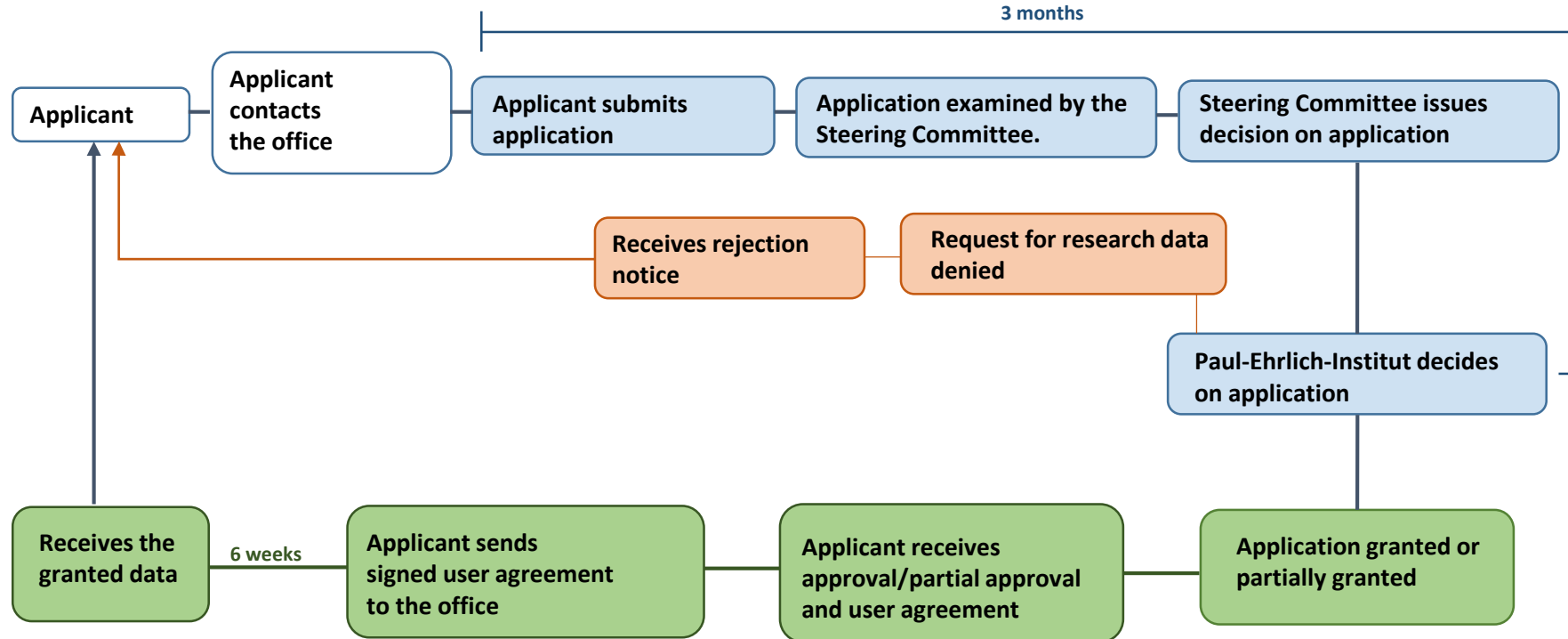


Haemophilia B patients Consumption 2020	Number [n]	patients that were treated [n]	plasma-derived FIX [IU]	recombinant FIX [IU]	recombinant FVIIa [IU]
Children and adolescents without inhibitors	225	167	1,478,800	11,339,000	100,050,000
Children and adolescents with inhibitors	1	1	0	140,000	0
Adults without inhibitors	634	445	12,542,000	43,938,200	114,750,000
Adults with inhibitors	0	0	0	0	0
<b>Total</b>	<b>860</b>	<b>613</b>	<b>14,020,800</b>	<b>55,417,200</b>	<b>214,800,000</b>

von Willebrand



von Willebrand patients Consumption 2020	Number [n]	patients that were treated [n]	FVIII preparations containing VWF [IU]	plasma-derived vWF [IU]	recombinant vWF [IU]
Total Consumption All Patients	5,562	794	35,809,200	12,627,300	1,709,500



Data can be requested from the DHR for research purposes. An application for research data can be submitted to the office of the DHR, which will also provide the necessary documents. After examination and decision by the steering committee of the dhr, the Paul-Ehrlich-Institut draws up a decision, the applicant signs a user agreement and receives the approved data.

We thank all patients,  
who provide their data to the DHR  
and the medical facilities  
that collect and submit this data.

**Dear Patients,**  
**we would be very pleased if you gave your consent to the submission of an individual report, because this is the only way we can collect the data that is so important for research. Please talk to your doctor.**