

Annual Report 2019

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Paul-Ehrlich-Institut 
Bundesinstitut für Impfstoffe
und biomedizinische Arzneimittel





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

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IGH

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Representatives of

Patient Organisations
DHG, IGH

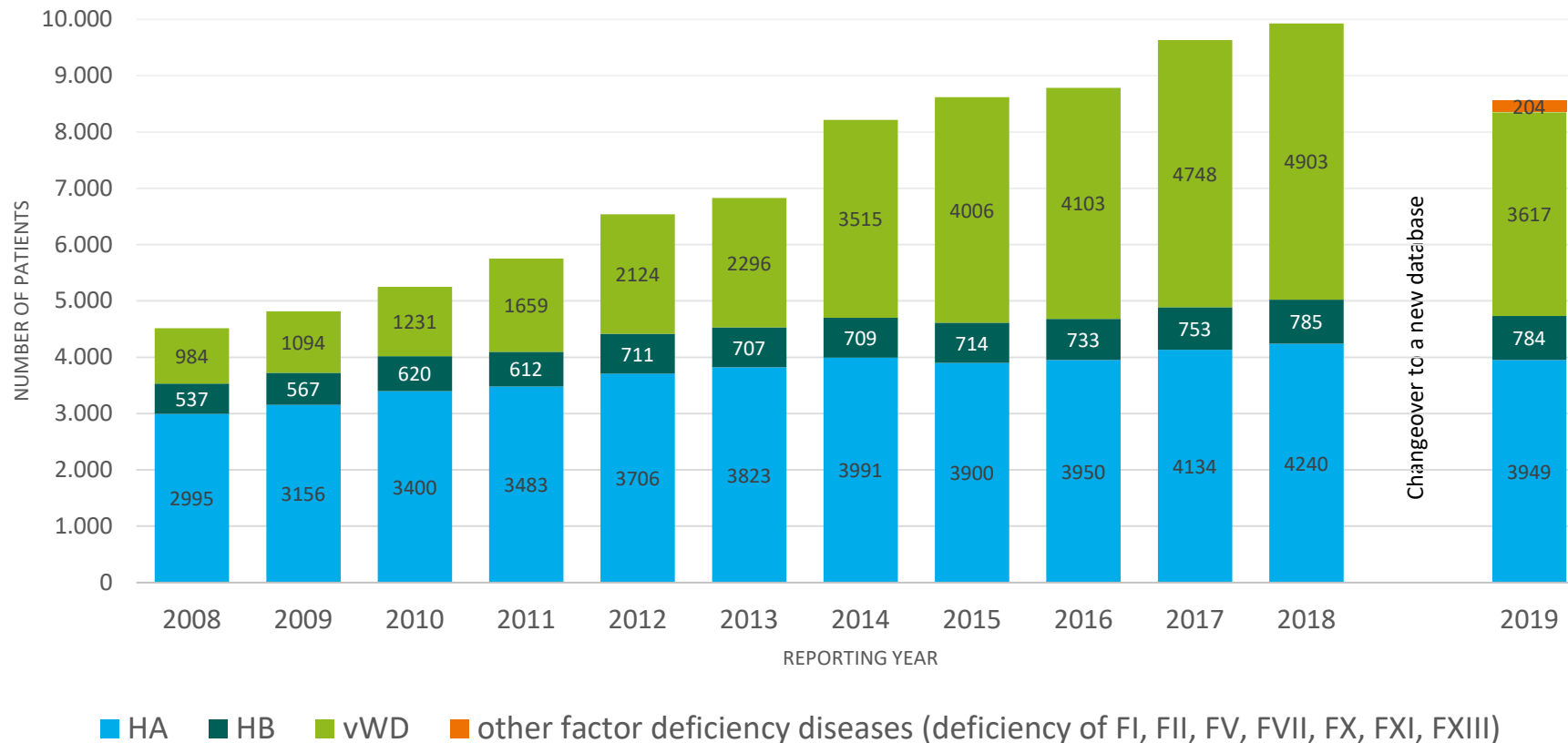
Medical Societies
BDDH, DGTI, GTH

Pharmaceutical industry associations
PPTA, VfA

National associations of health insurers
GKV-Spitzenverband

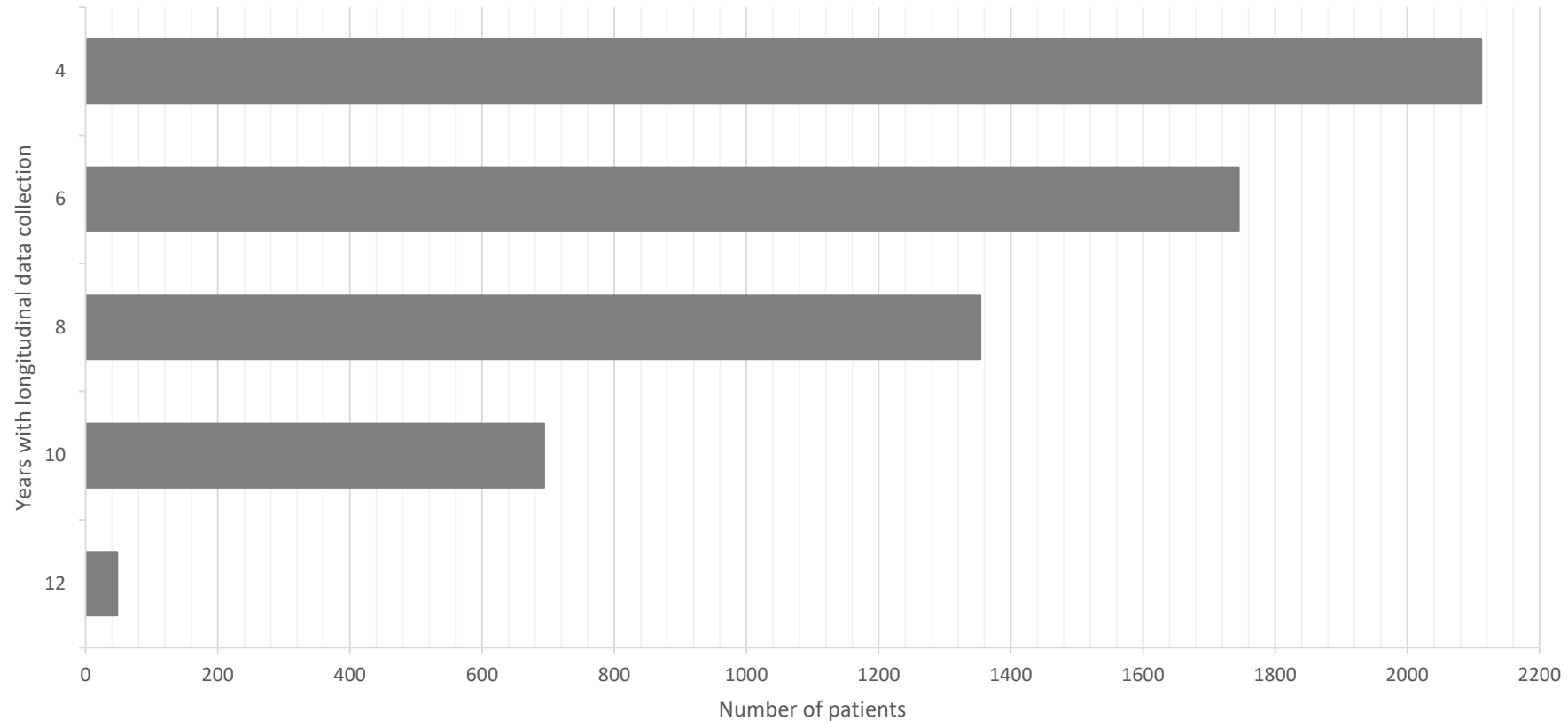
Private health insurer associations
PKV

Health care providers associations
DKG, KBV

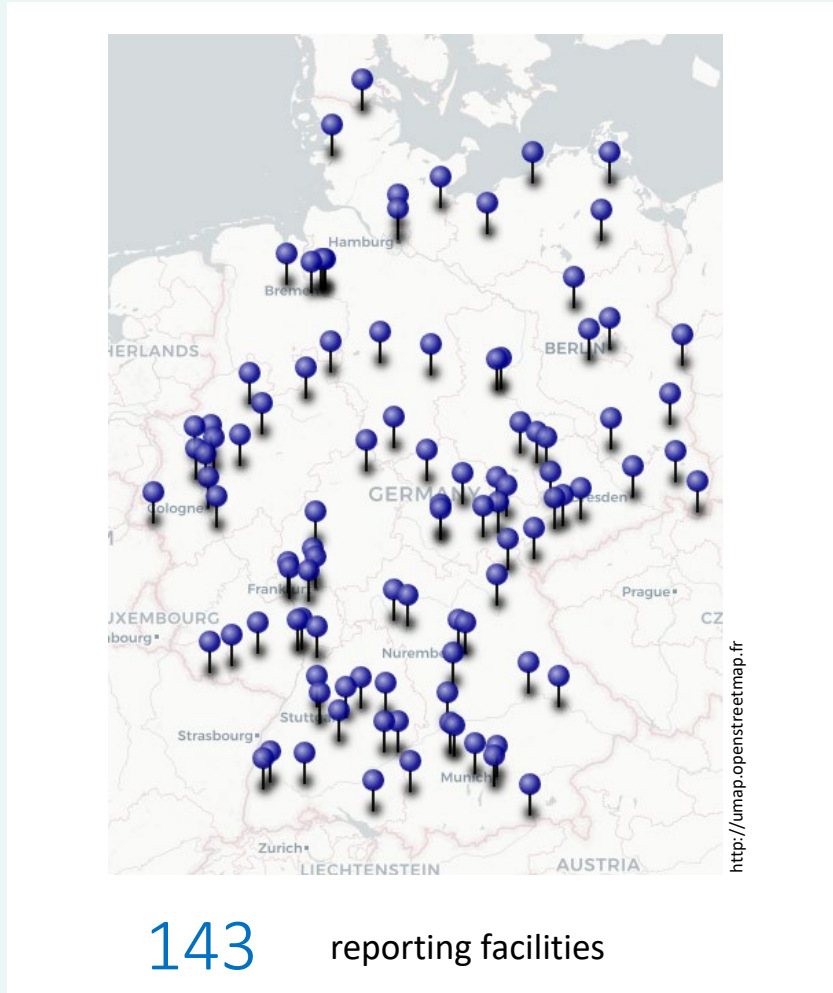
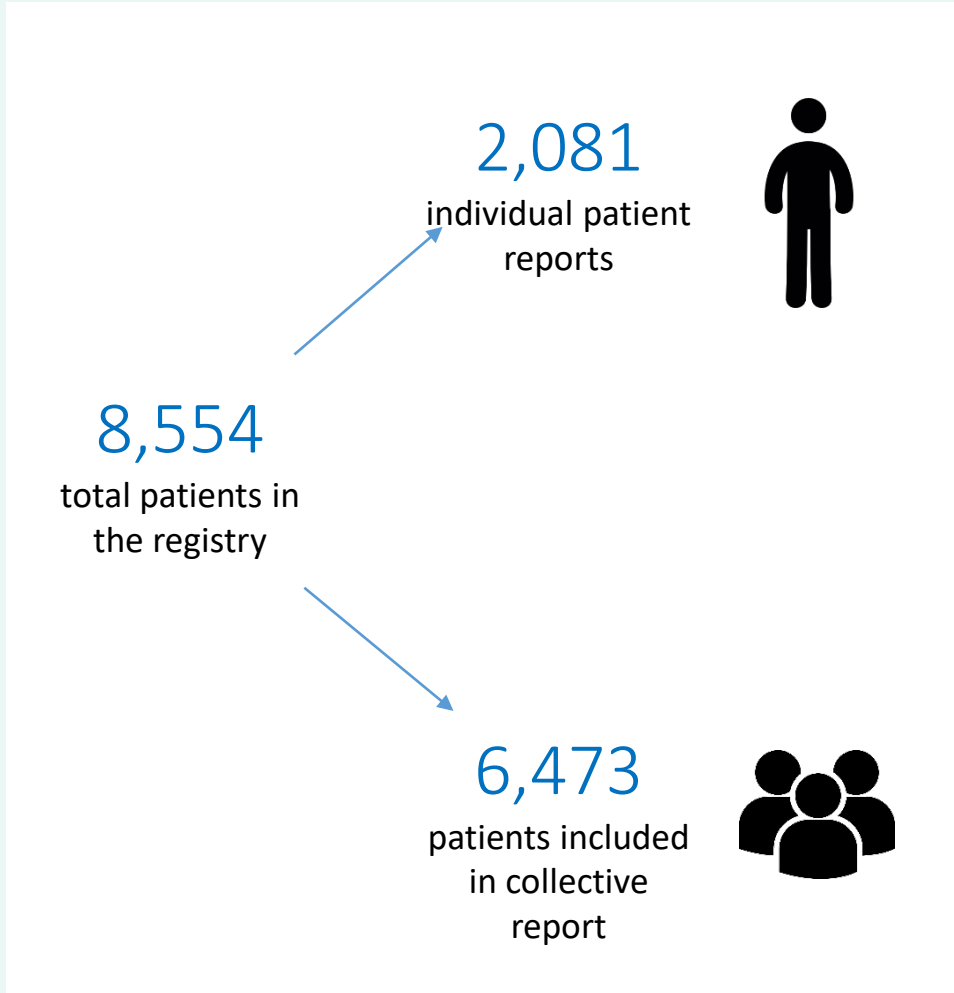


Since 2008, the DHR has been collecting specific data from individuals with blood coagulation disorders in Germany.

Due to the expansion of the Transfusion Act in 2019, the conversion to the new software became necessary. Since then, in addition to individuals with Haemophilia A (HA), Haemophilia B (HB) and von Willebrand disease (vWD), those with other rare inherited bleeding disorders caused by deficiency of coagulation factors must now also be reported in individual or collective reports.

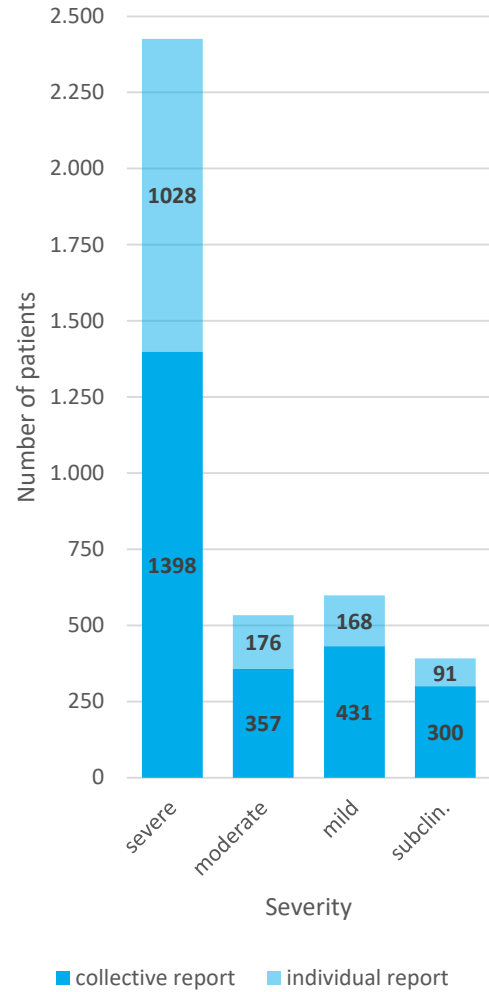


The DHR is set up as a register that can follow affected patients from birth onwards throughout their entire life. This longitudinal data collection, i.e. the course of the disease and treatment of a person, provides the most valuable data for research. The data is collected in pseudonymised form, so that no conclusions can be drawn about individual persons from the data. 48 data subjects have donated their data to the DHR via individual reports since the start of the registry, so that 12 years of data has now been recorded. Data from 694 data subjects has been collected for 10 years. And for over 2,100 patients, the DHR has 4 years of data.

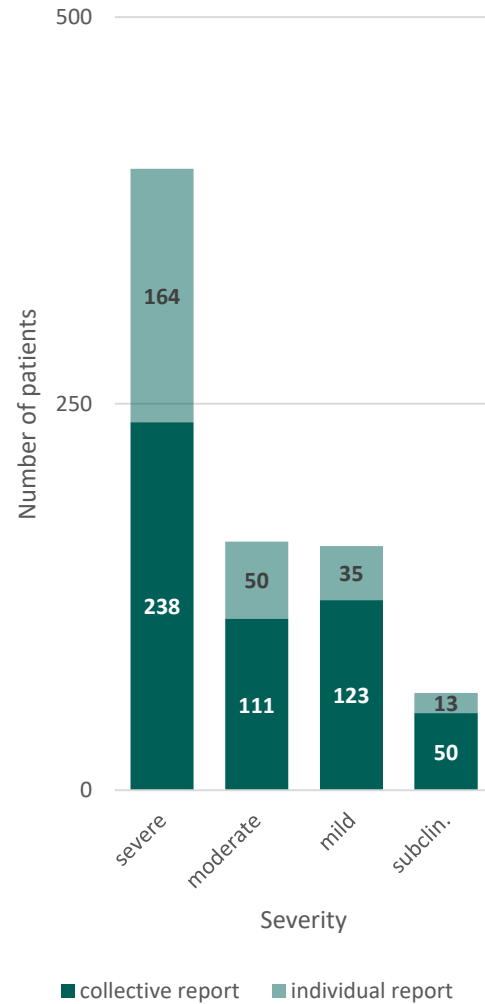


In 2019, 143 clinics, treatment centers and specialized medical practices reported data for a total of 8,544 people. 2,081 patients have given their consent to an individual report and 6,473 patients were recorded via collective reporting.

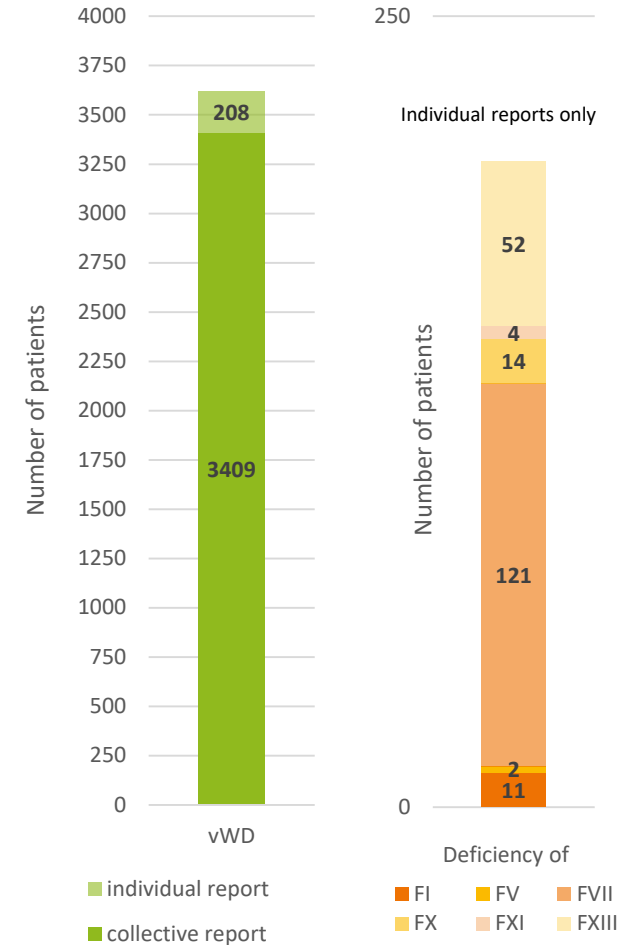
Haemophilia A



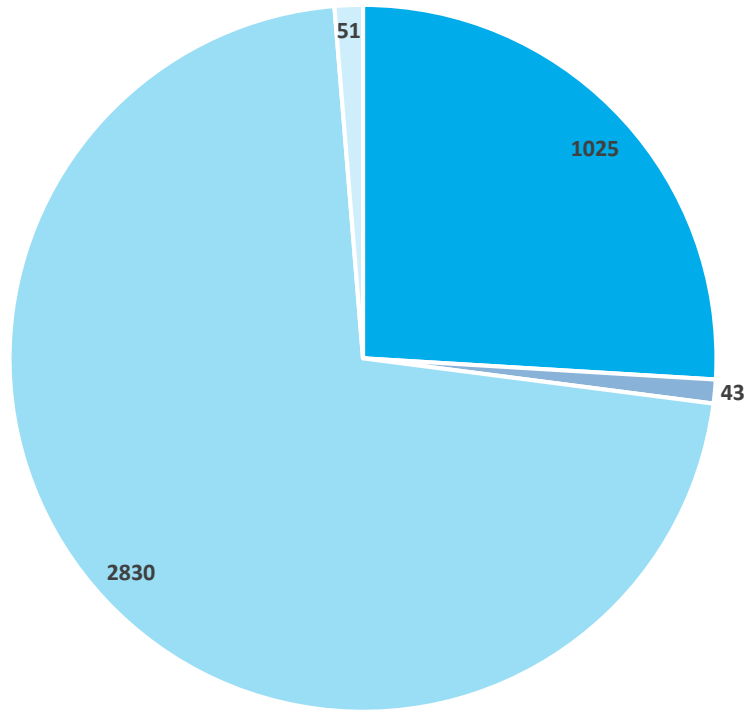
Haemophilia B



vWD and other factor deficiency diseases

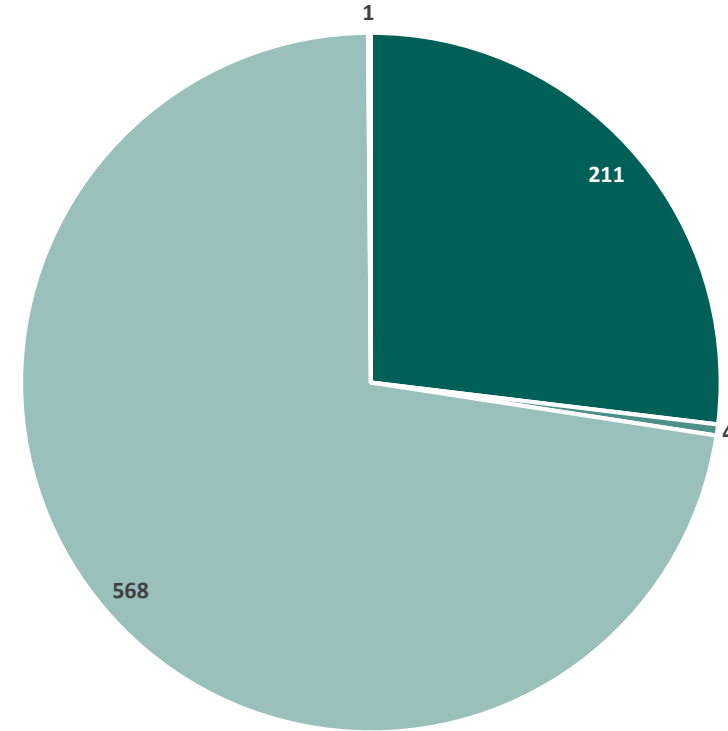


Haemophilia A



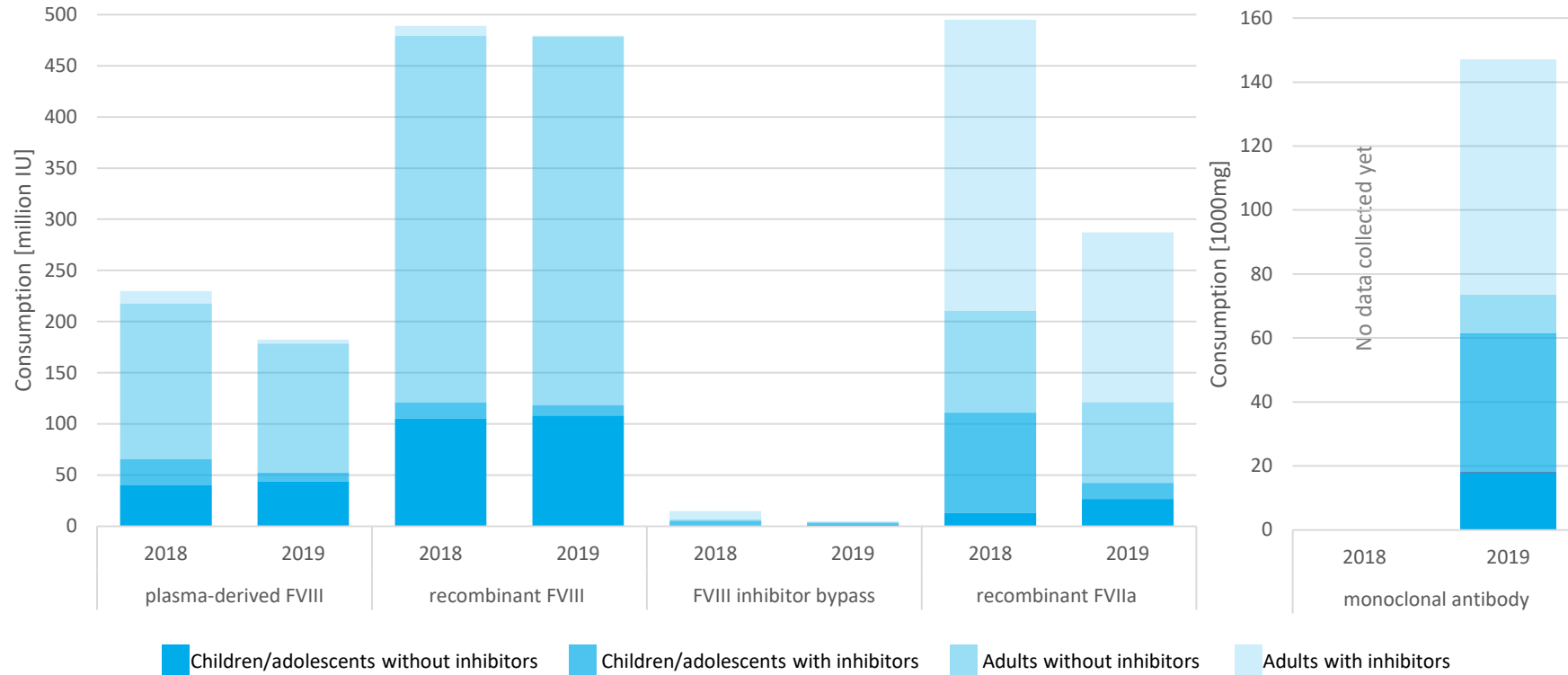
- children and adolescent without inhibitors
- children and adolescent with inhibitors
- adults without inhibitors
- adults with inhibitors

Haemophilia B



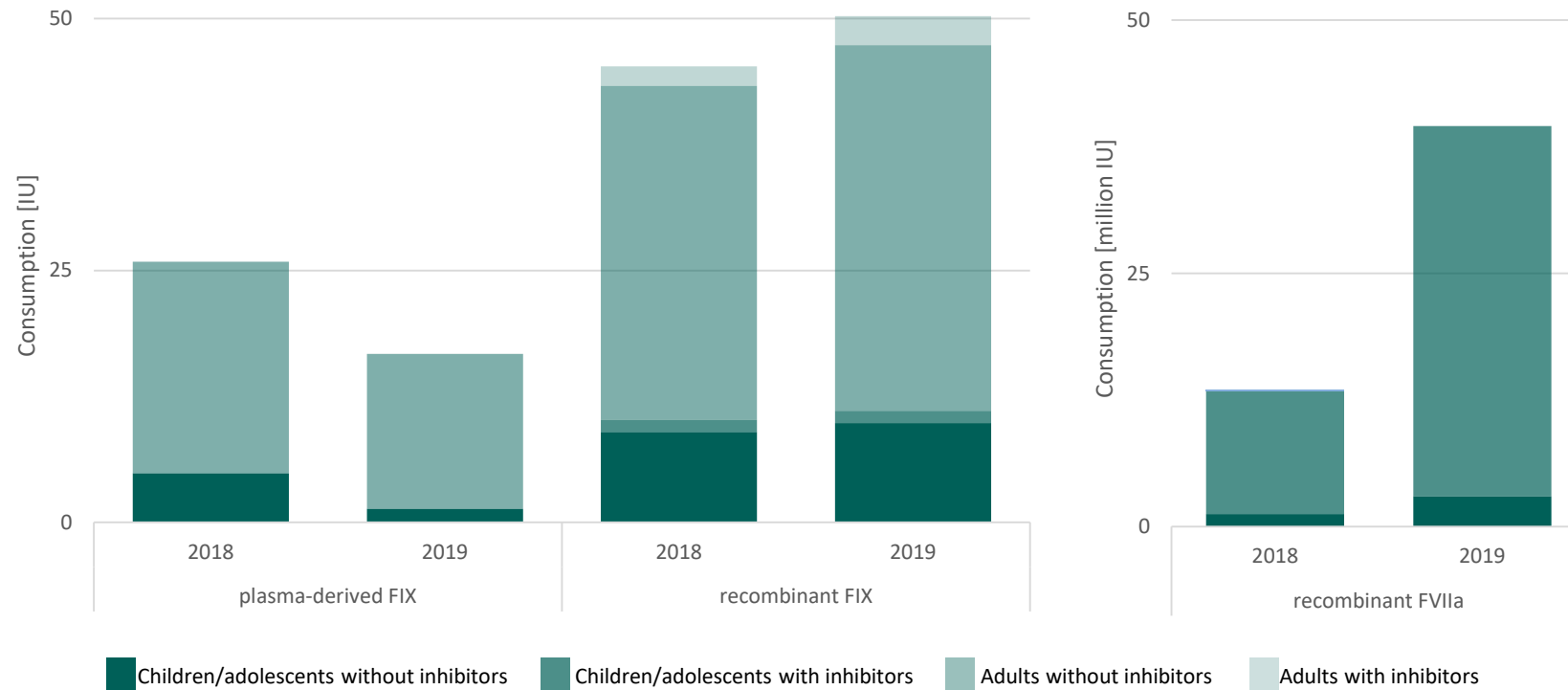
- children and adolescent without inhibitors
- children and adolescent with inhibitors
- adults without inhibitors
- adults with inhibitors

Haemophilia A



Haemophilia A patients in need of substitution consumption 2019	Number [n]	plasma-derived FVIII [IU]	recombinant FVIII [IU]	FVIII inhibitor bypass [IU]	recombinant FVIIa [IU]	monoclonal antibody [mg]
Children and adolescents without inhibitors	1,025	43,886,705	108,132,573	1,795,000	26,700,000	17,600
Children and adolescents with inhibitors	43	8,425,750	10,244,220	1,555,000	15,750,000	510
Adults without inhibitors	2,830	126,063,015	359,828,530	591,000	78,700,000	43,050
Adults with inhibitors	51	4,132,360	1,198,548	1,224,000	166,050,000	12,360
Total	3,949	182,507,830	479,403,871	5,165,000	287,200,000	73,520

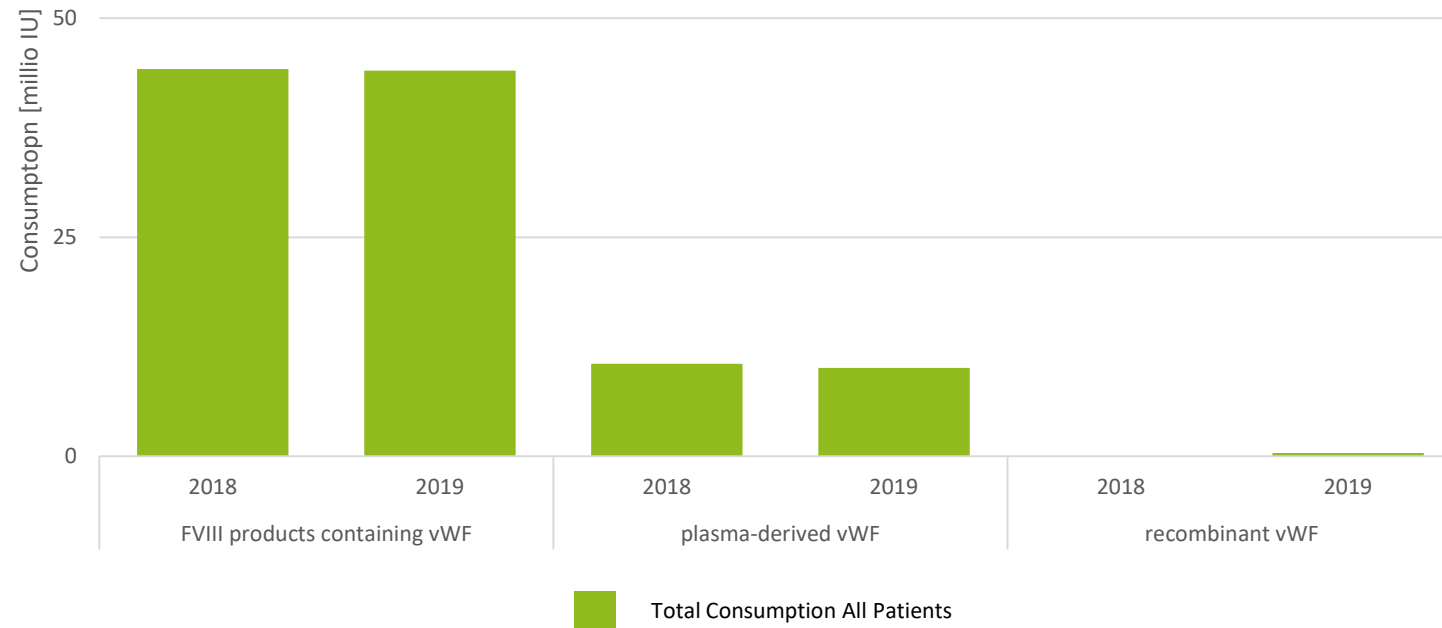
Haemophilia B



Haemophilia B patients in need of substitution, Consumption 2019	Number [n]	plasma-derived FIX [IU]	recombinant FIX [IU]	recombinant FVIIa [IU]
Children and adolescents without inhibitors	211	1,346,600	9,860,050	3,000,000
Children and adolescents with inhibitors	4	0	1,219,000	36,550,000
Adults without inhibitors	568	15,366,800	36,268,950	0
Adults with inhibitors	1	0	2,900,000	0
Total	784	16,713,400	50,248,000	39,550,000



vWD



von Willebrand patients in need of substitution Consumption 2019	Number [n]	FVIII products containing vWF [IU]	plasma-derived vWF [IU]	recombinant vWF [IU]
Total Consumption All Patients	3,617	43,993,700	10,100,400	359,950

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