

Annual Report 2021

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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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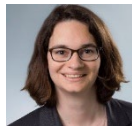
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For the Patient Organisations

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Dr. Anna Griesheimer

IGH

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For the medical society
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For the Federal Institute
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Dr. Christine Keipert
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Scientific Committee

Representatives of

Patient Organisations
DHG, IGH

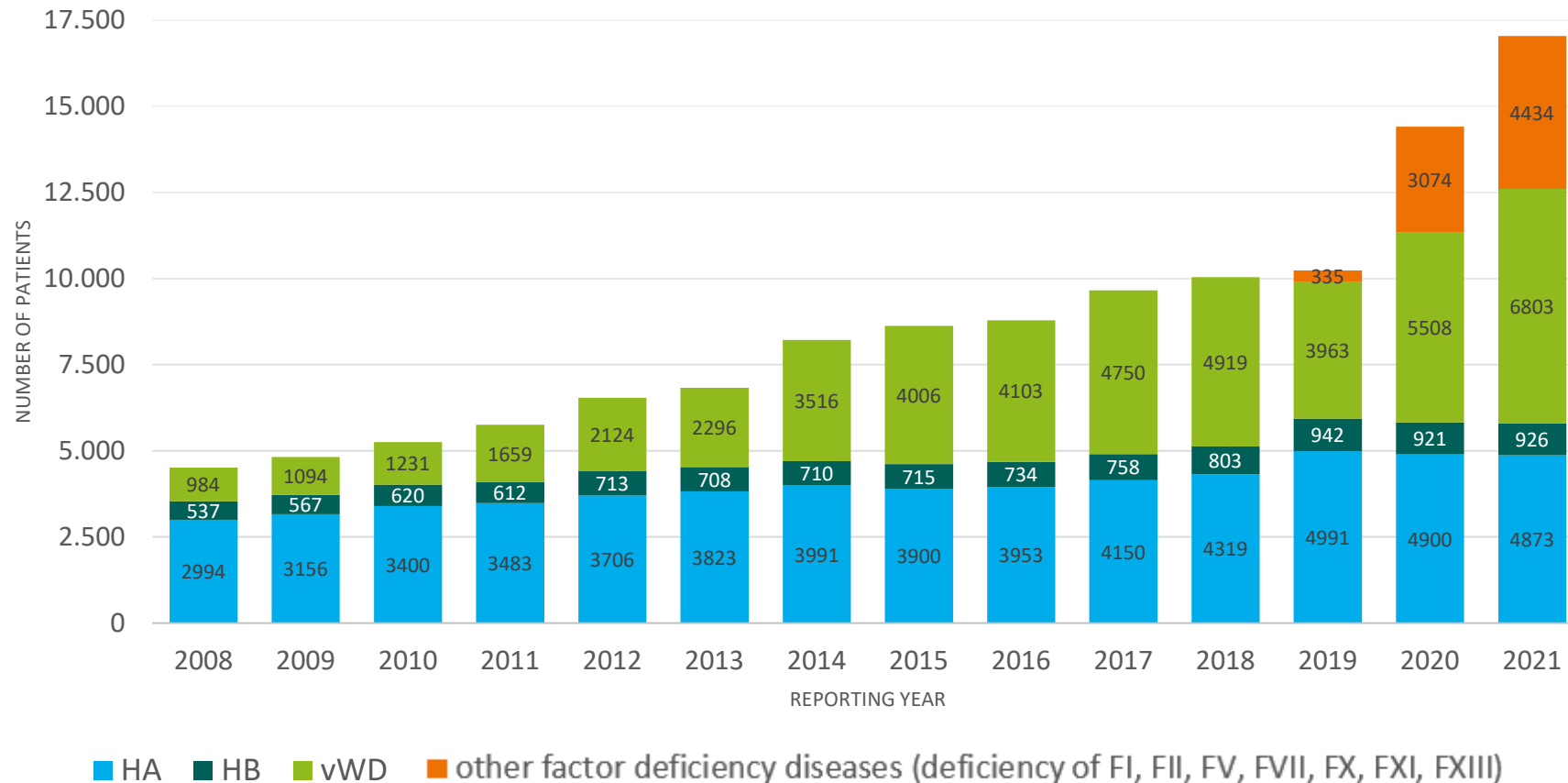
Medical Societies
BDDH, DGTI, GTH

Pharmaceutical industry associations
PPTA, VfA

National Association of Statutory Health
Insurance Funds
GKV-Spitzenverband

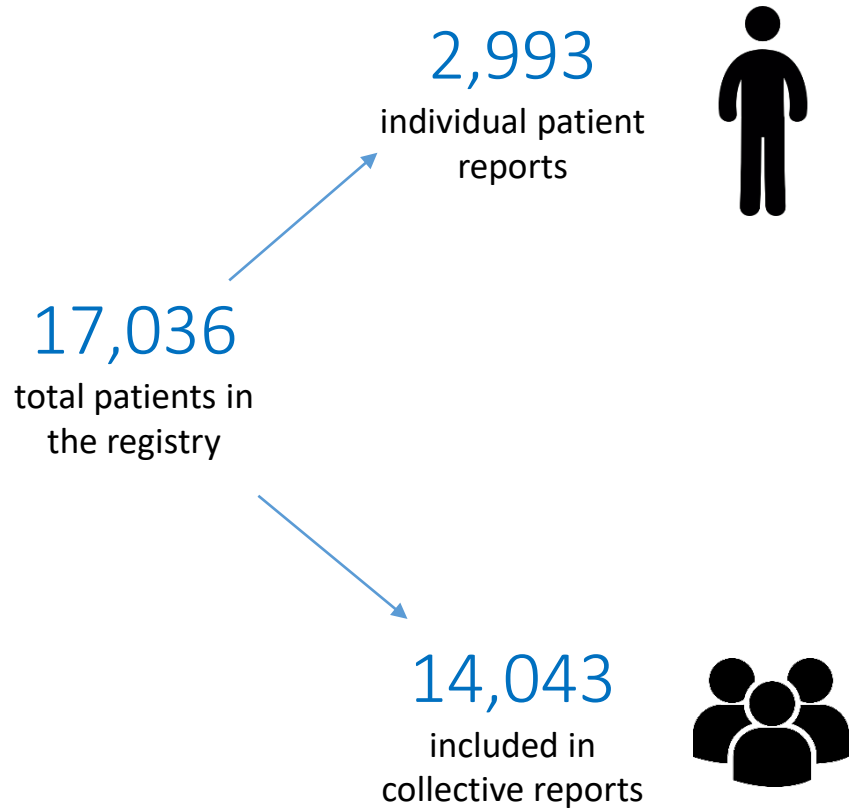
Private health insurer associations
PKV

Healthcare provider associations
DKG, KBV



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

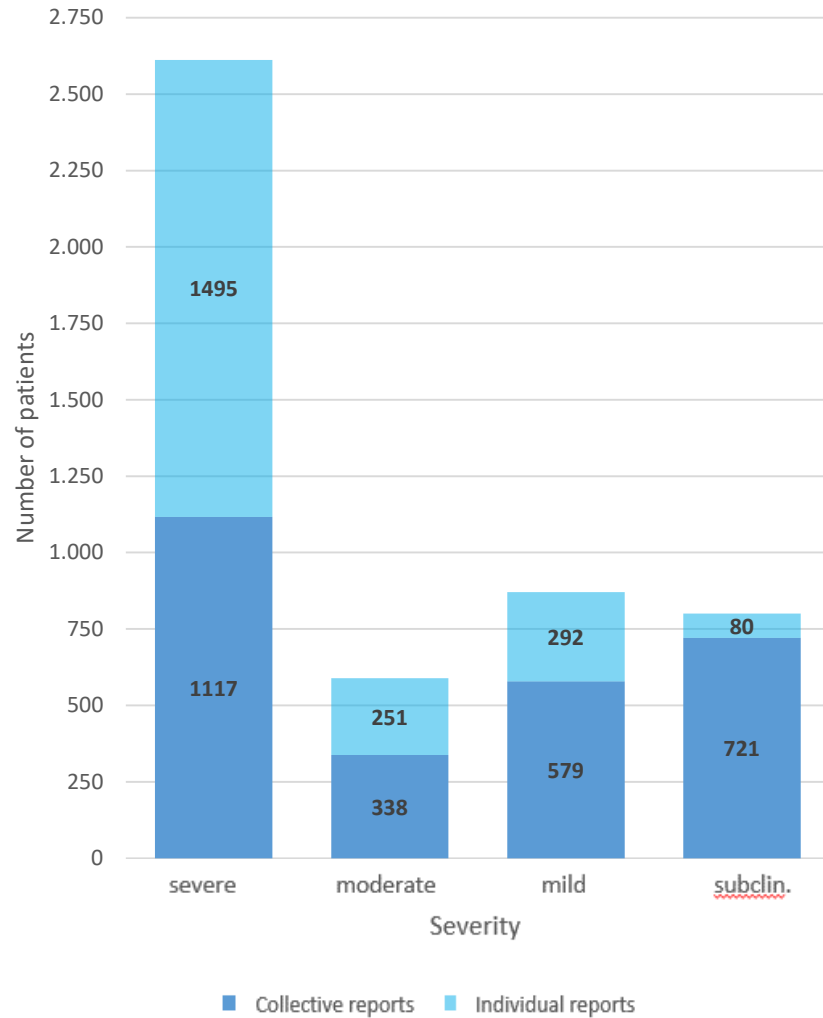
Since the expansion of the Transfusion Act in 2019, in addition to persons with haemophilia A (HA), haemophilia B (HB) and von Willebrand disease (vWD), individuals with other factor deficiency diseases must now also be included in individual or collective reports. The DHR has collected data from more than 17,000 patients since 2021.



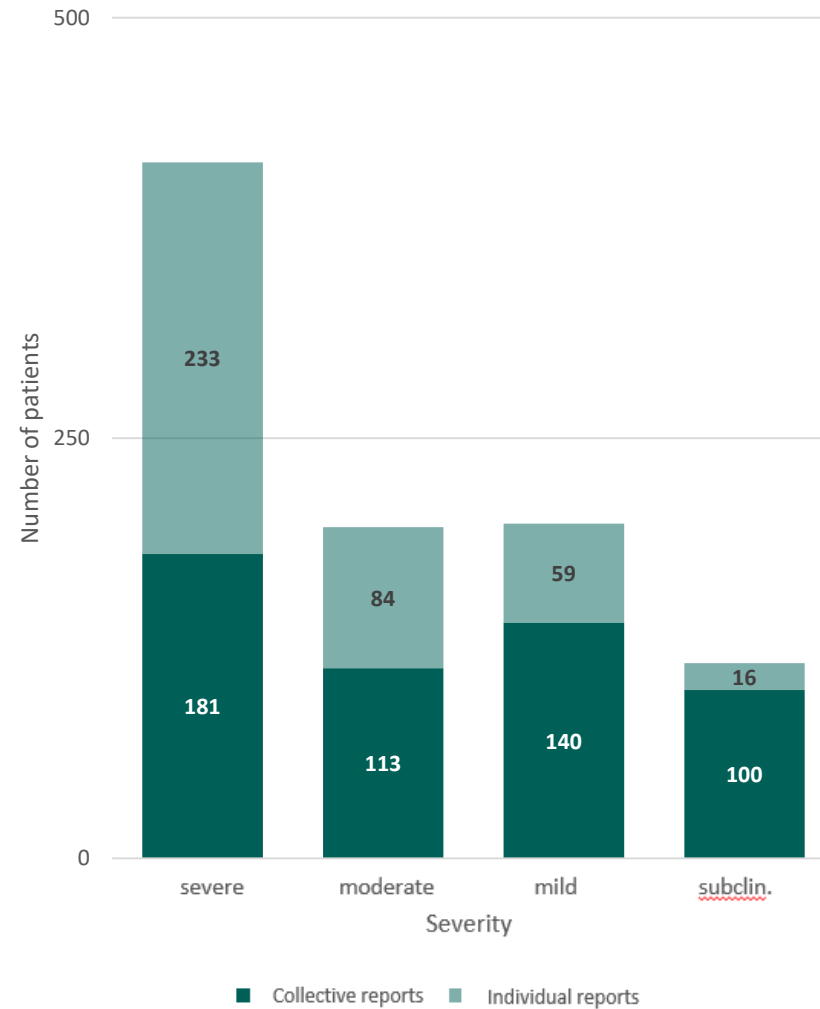
137 reporting facilities

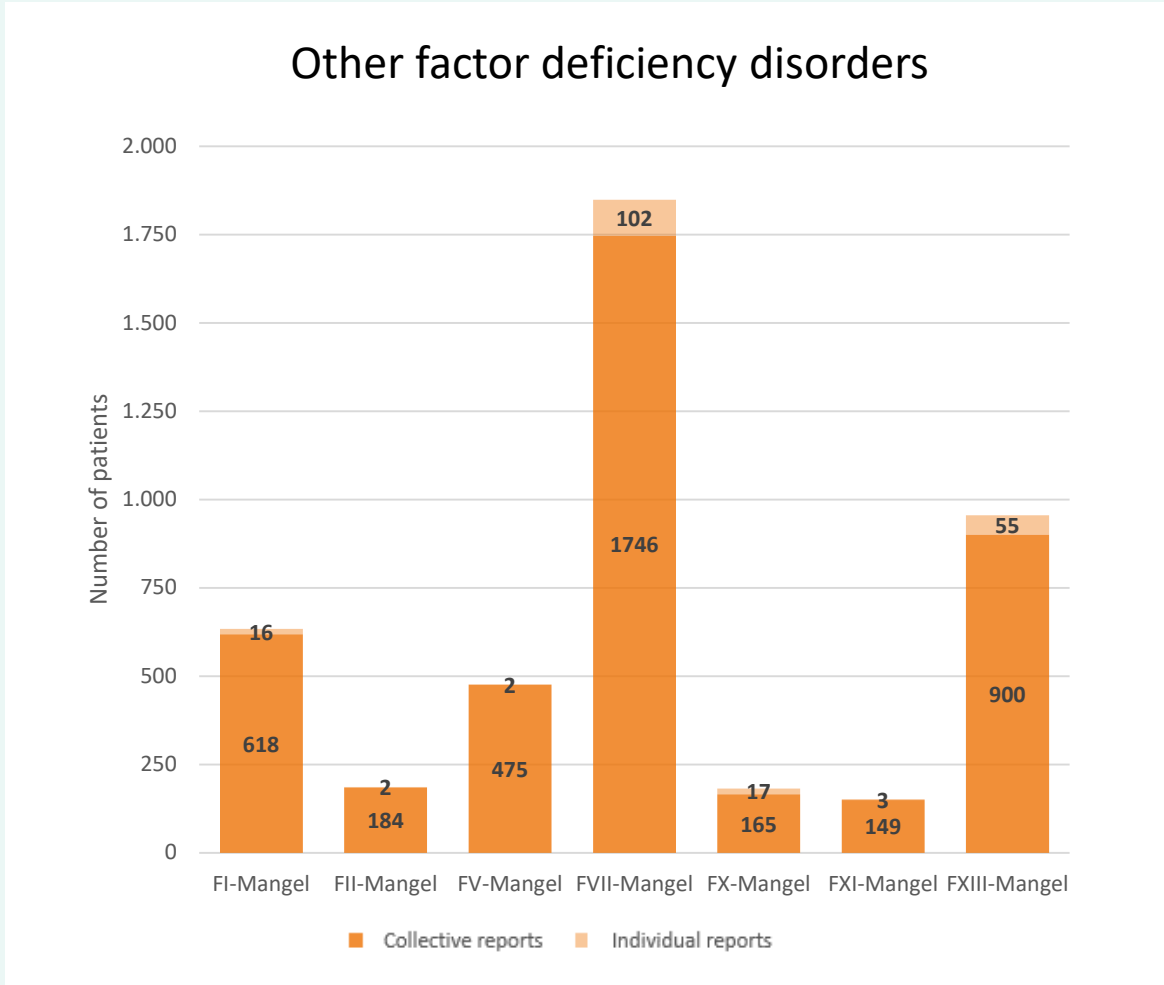
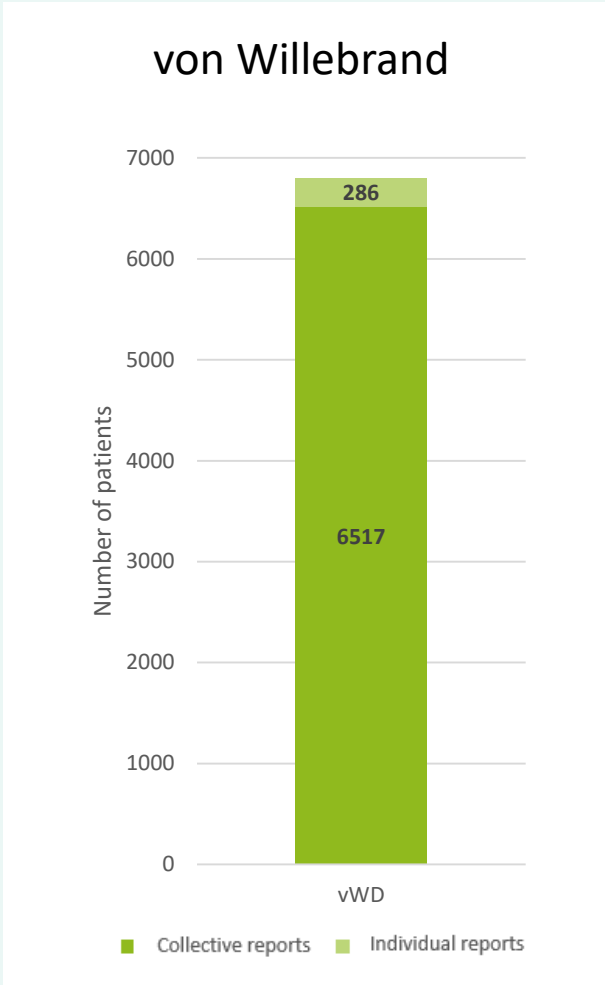
In 2021, 137 clinics, treatment centres, and specialised medical practices reported data from a total of 17,036 patients. 2,993 patients gave their consent to an individual report. That is 514 more patients than in 2020 and 911 more patients than in 2019. 14,043 patients were recorded via the collective report.

Haemophilia A



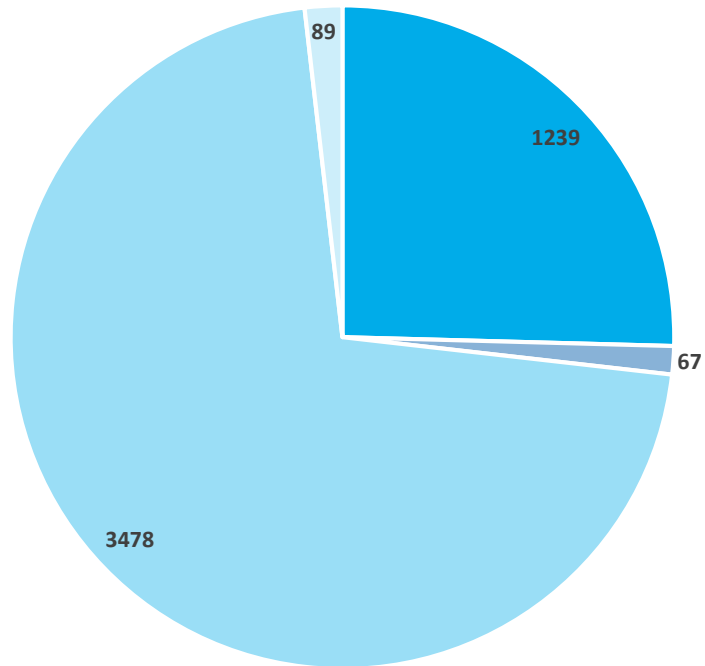
Haemophilia B





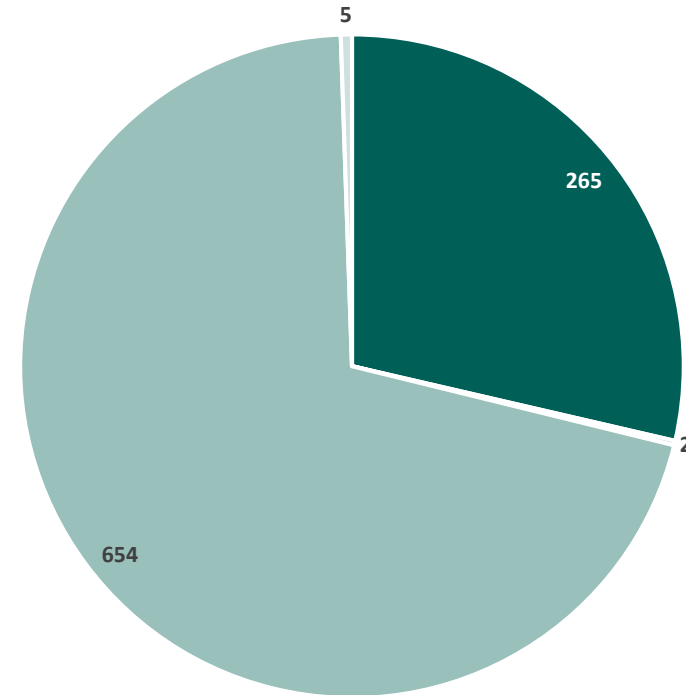
In 2021, a total of 6,803 patients with von Willebrand disease and 4,434 patients with other factor deficiency diseases were reported to the DHR. Only a small proportion of von Willebrand patients require treatment with coagulation products.

Haemophilia A



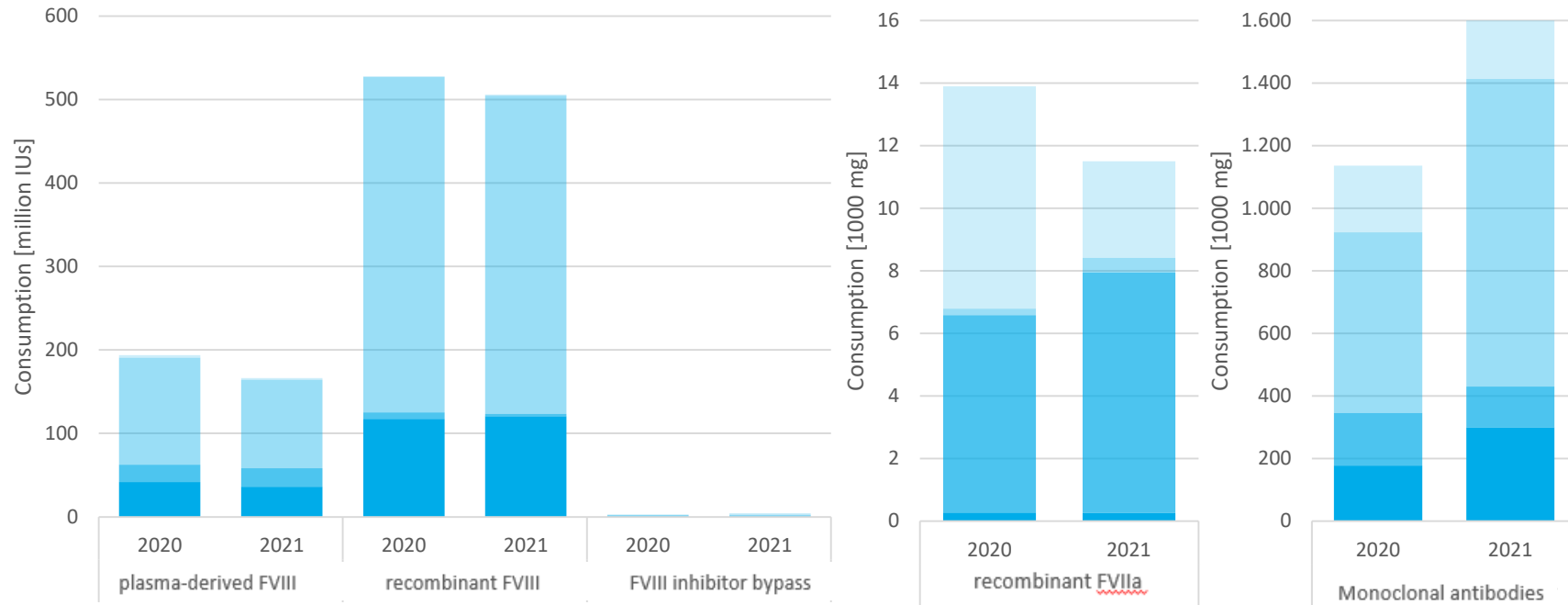
- Children/adolescents without inhibitors
- Children/adolescents with inhibitors
- Adults without inhibitors
- Adults with inhibitors

Haemophilia B



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

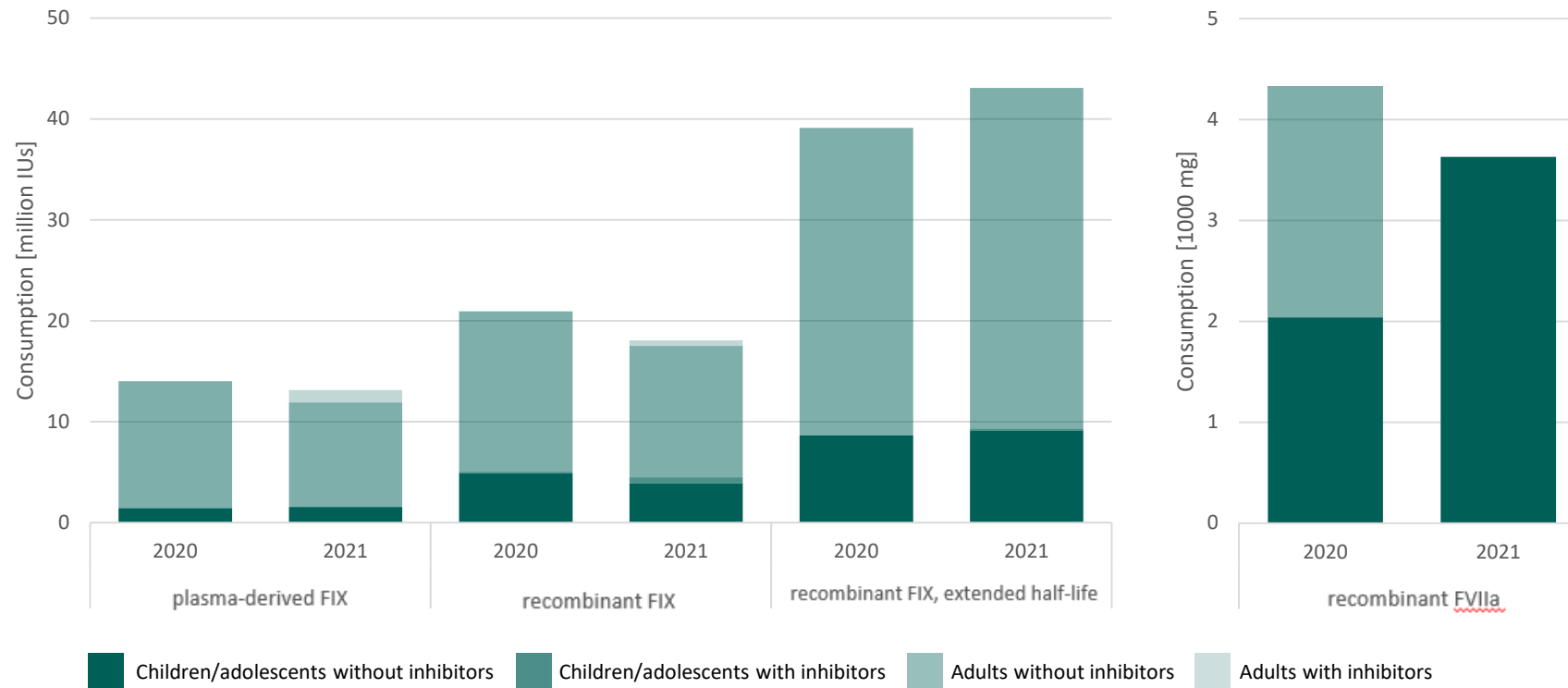
Haemophilia A



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

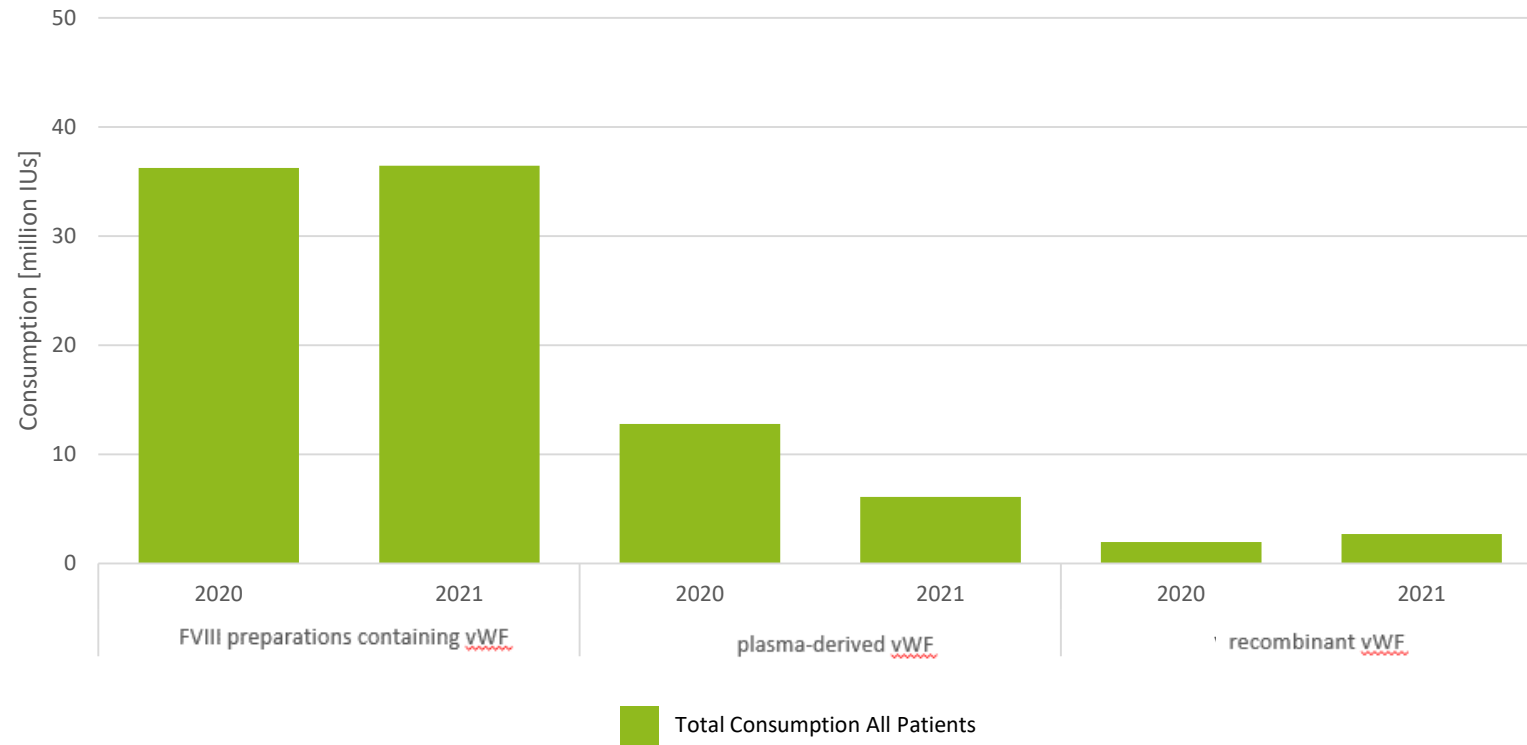
Haemophilia A patients Consumption 2021	Number [n]	patients that received treatment [n]	plasma-derived FVIII [IU]	recombinant FVIII [IU]	FVIII inhibitor bypass [IU]	recombinant FVIIa [mg]	monoclonal antibodies [mg]
Children and adolescents without inhibitors	1,239	952	36,097,300	120,590,077	0	265	299,703
Children and adolescents with inhibitors	67	65	22,009,300	2,653,250	1,557,000	7,673	129,797
Adults without inhibitors	3,478	2,384	106,073,018	381,478,106	1,075,000	469	982,937
Adults with inhibitors	89	58	2,251,000	1,301,000	1,608,000	3,095	187,345
Total	4,873	3,459	166,430,618	506,022,433	4,240,000	11,502	1,599,782

Haemophilia B

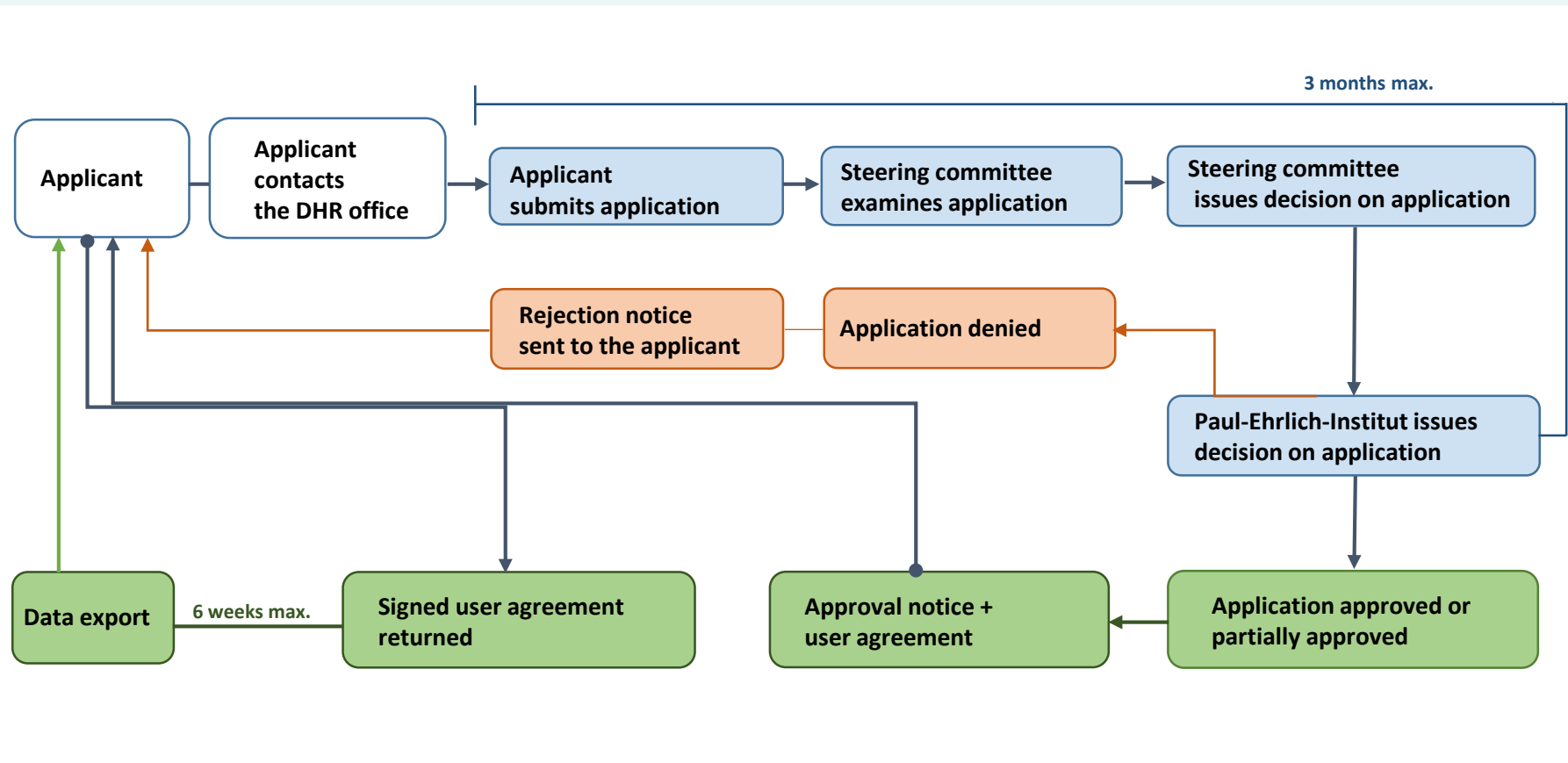


Haemophilia B patients Consumption 2021	Number [n]	patients that were treated [n]	plasma-derived FIX [IU]	recombinant FIX [IU]	recombinant FIX, extended half-life [IU]	recombinant FVIIa [IU]
Children and adolescents without inhibitors	265	186	1,550,500	3,891,800	9,068,500	3,630
Children and adolescents with inhibitors	2	2	0	597,000	246,000	0
Adults without inhibitors	654	452	10,353,000	13,015,000	33,765,000	0
Adults with inhibitors	5	4	1,227,600	547,500	0	0
Total	926	644	13,131,100	18,051,300	43,079,500	3,630

von Willebrand

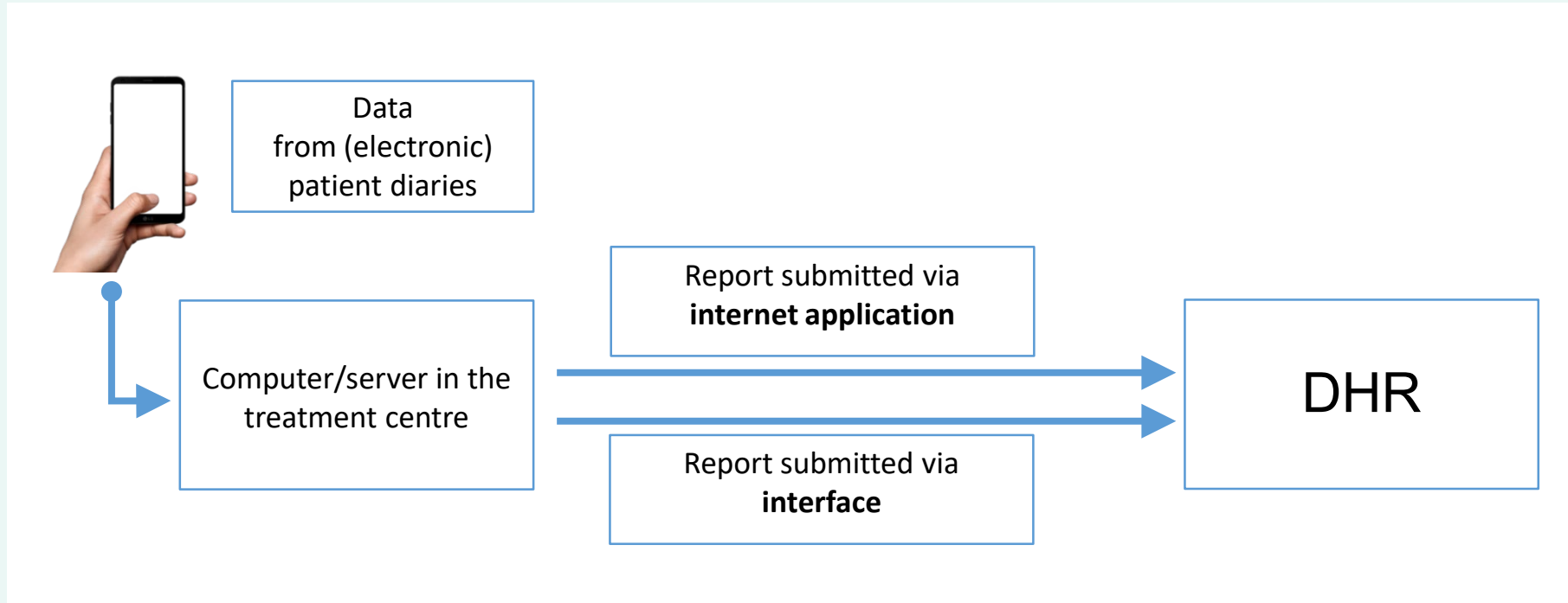


von Willebrand patients Consumption 2021	Number [n]	patients that were treated [n]	FVIII preparations containing vWF [IU]	plasma-derived vWF [IU]	recombinant vWF [IU]
Total Consumption All Patients	6,803	974	36,456,200	6,105,100	2,677,800



Data can be requested from the DHR for research purposes:

The documents needed to submit a request are available at www.pei.de/dhr. Applications can only be submitted after consultation with the DHR office. After examination and decision by the DHR steering committee, the Paul-Ehrlich-Institut issues the final decision. Applicants will receive a user agreement and the policies for publication when they receive the decision on their application. Once the applicant has returned a signed user agreement, they will receive the data to which they have been granted access.



We would be very pleased if you would 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.

It is also important to know that you as a patient are obliged to document your consumption and that you must pass on the data you've collected to your attending physician at least once a year. If you use an electronic patient diary for the documentation of your treatment, the information can be transmitted to the DHR via the treatment centre server without having to enter it again manually in the internet application. This makes it easier for contributors to submit reports and at the same time helps to avoid transmission errors. You are encouraged to discuss using an electronic patient diary with the patient organisations DHG and IGH or your doctor.

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