

## Introduction

Inborn errors of immunity (IEI) are rare, difficult-to-manage disorders caused by inherited defects in cells of the immune system. They can result in increased risk of life-threatening infections or autoimmune diseases. Rare Immunodeficiencies do not have any causal treatment yet. This study analyses claims from a German payer database to better understand the follow-up and therapies required for patients living with IEIs and the antibiotic usage of those patients.

### Method

#### RETROSPECTIVE CONGITUDINAL STUDY 07/2019 – 06/2023

**Data source:**  
Claims data of BARMER sickness fund, about 8.5 million insurees.

All patients with diagnosis of (any) immunodeficiency (KD-10 D81.8, D81.9, D83\* and D84\*)

N=40.630

Prescriptions

Outpatient care (diagnoses and procedures)

Patient master data

### Results: Patient numbers and age and sex Distribution

	Patients with immunodeficiency (ICD: D81.8, D81.9, D83*, D84*)		
Age in 2022	M	F	Total
0-9 years	2.335	1.946	4.281
10-19 years	1.940	1.874	3.814
20-29 years	1.349	2.099	3.448
30-39 years	1.475	2.721	4.196
40-49 years	1.387	2.955	4.342
50-59 years	1.774	4.000	5.774
60-69 years	1.869	4.255	6.124
70-79 years	1.341	3.179	4.520
80-89 years	1.077	2.385	3.462
>= 90 years	193	476	669
<b>Total</b>	<b>14.740</b>	<b>25.890</b>	<b>40.630</b>

Projected to the German statutory insured population, about 345k patients suffer from any kind of immunodeficiency.

### Results: Treatment with antibiotics and / or corticosteroids

Antibiotics	Corticosteroids	Number patients
∅	∅	11.682
∅	ü	2.975
ü	∅	14.516
ü	ü	11.457
<b>Total</b>		<b>40.630</b>

#### Results: patients with two or more antibiotic treatment courses between May and October („off season“)

Patients up to 11 years	
Year	Number patients
2019	192
2020	144
2021	252
2022	330
2023	104
<b>Total</b>	<b>1.022</b>

Patients aged 12 and over	
Year	Number patients
2019	1.776
2020	2.094
2021	2.226
2022	2.433
2023	682
<b>Total</b>	<b>9.211</b>

#### Results: patients over 12 with four or more antibiotic treatment courses per year

Year	patients older than 12 years with >= 4 VO	Number patients with diagnose J....	%
2019	585	135	23,08%
2020	1.484	311	20,96%
2021	1.289	249	19,32%
2022	1.472	316	21,47%
2023	533	137	25,70%
<b>Total</b>	<b>5.363</b>	<b>1.148</b>	<b>21,41%</b>

Between 137 and 316 patients (Barmer, equivalent to 1,200 – 2,700 statutory health insurance patients) per year are 'suspected cases' of severe immunodeficiency and should be screened for APDS.

## Discussion / Conclusion

About 40 thousand of BARMER-insured patients do have a diagnosis of (any) immunodeficiency, which means about 350 thousand in Germany. Women are affected more than man.

71% of the patients diagnosed get a more or less specific treatment, about 25% get prescriptions of antibiotics and corticosteroids.

About nine thousand of the BARMER insured patients with immunodeficiency get minimum two antibiotics treatment courses between May and October ("off season"), and between 137 and 316 patients per year do have more than four antibiotic courses per year and additionally a diagnosis of a chronic lung disease (i.e. Bronchiectasis):

Claims data analysis seems to be able to identify the patients at risk. Together with the new legal possibilities to reach out patients at risk by their sickness funds (§25b SGB V) this might be an interesting option to speed up differential diagnosis and enable causal treatment (if existent) for primary immune defects.