

German Cystic Fibrosis Registry

Annual Report | 2024

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Preamble



Prof. Dr. med. Lutz Nährlich

Medical director German Cystic
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With the 2024 report, the German Cystic Fibrosis Registry presents the current health status of people with cystic fibrosis (PwCF) in Germany, the developments of the last two decades, and the trends for selected birth cohorts.

For the first time, the report is being made available not only in PDF format but also interactively in MUKOweb and MUKOme, as well as in excerpts on www.muko.info. This is a significant step towards more intensive use of the registry data. My special thanks go to Manuel Burkhart and Bärbel Jaumann for their excellent development work.

The living population in the German Cystic Fibrosis Registry 2024 has reached a new record high with 7,771 people with cystic fibrosis – 7,369 of whom (95% of the living population) have history data. Meanwhile, 63% of all people with cystic fibrosis are 18 years and older. CFTR modulator therapy was available for 88% of all people with cystic fibrosis in Germany in 2024 and was used in 91% of this group. The report illustrates the medium-term impact on the health status of all people with cystic fibrosis. It should be noted that the presentation does not distinguish between people with cystic fibrosis with or without CFTR modulator therapy and therefore only partially reflects the individual effect. The median survival age of all people with cystic fibrosis in Germany rose to 66.8 years for the current period (2020-2024).

The stabilization of lung function continues across all birth cohorts. Among 18–19-year-olds, 86% have an FEV1%pred of over 80%, compared to 32% in the year 2000. The rate of chronic *Pseudomonas* infections has further decreased to 6.2% in children and adolescents and 45% in adults. Another positive development is the consistently high rate of PwCF without exacerbations treated with antibiotics (70%) and without hospitalizations (83%). The decline in underweight, particularly among adults, is offset by an increase in overweight and obesity, which remains stable compared to the previous year. Basic and indication therapy shows a further reduction in the treatment burden. All of this underscores the ongoing necessity for close clinical care by the multidisciplinary cystic fibrosis team to collectively capture and discuss medium-term changes and future challenges. The German Cystic Fibrosis Registry can provide the (data) basis for this and also makes it available to people with cystic fibrosis through the "MUKOme" patient portal.

This detailed overview of the health status of people with cystic fibrosis would not be possible without your trust in the German Cystic Fibrosis Registry. I would like to sincerely thank all outpatient clinic teams and the people with cystic fibrosis who, with their consent, enable us to document and evaluate their data. A warm thank you to everyone involved in data entry and evaluation. My thanks also go to the Registry Working Group (AG Register), the company axaris (Ms. Jaumann, Mr. Müller, Mr. Volk), and the data management team at the Interdisciplinary Center for Clinical Trials (IZKS) of the University of Mainz (Ms. Wosniok, Ms. Wollscheid, Ms. Adams (formerly Endres), Mr. Kronfeld, Mr. Ruckes). My special thanks go to Mr. Burkhart from the Cystic Fibrosis Institute for his tireless commitment to project management.

Please remain supportive of the registry.

Collective description

For report year 2024, history datasets of 7.369 patients are included in the evaluations of demography, Cystic Fibrosis diagnosis, mortality and structure of care. In the evaluations of CF new diagnoses and mortality, patients without history data were also considered (43 newly diagnosed and 19 deceased without history datasets 2024).

All 438 transplanted patients, regardless of the type of transplantation, were excluded from the evaluations of nutritional status, lung function, lung infections, complications and therapies. This results in a number of 7.028 patients for the analysis of history data.

For the different analysis collectives, further definitions apply in part, which are described in more detail in the corresponding chapters.

For all evaluated patients, a current declaration of consent is available or they deceased before a new consent could be obtained. Patients who withdrew their consent before death were excluded from mortality analyses.

The age of patients not documented as deceased was calculated at the end of the respective report year in completed years. For patients who deceased in the report year, age at the time of death was calculated in completed years. For deceased patients where no date of death was documented, age was calculated in completed years at the end of the report year. The age of newly diagnosed patients was calculated at the time of diagnosis.

Lung function was calculated and presented using the reference values of the Global Lung Function Initiative (GLI) (Quanjer et al; Eur Respir J2012; 40: 1324).

For the calculation of BMI percentiles for 2 – 18-year-old patients, the reference values according to the KiGGS study were used (Robert Koch Institute: Reference percentiles for anthropometric measurements and blood pressure from the Study on the Health of Children and Adolescents (KiGGS); Berlin: RKI-Hausdruckerei; 2013).

Missing values were not taken into account for the calculation of percentages.

History datasets are aggregated from the visit-related datasets of the clinics. For patients older than 6 years with a lung function measurement, the examination time with the best FEV1%pred and the associated body measurements are selected as the examination date in the report year. In case of a missing FEV1 value and for children younger than 6 years, the last available body measurements in the report year are used. A complication or long-term therapy, a microbiological detection or a chronic infection present at least once a year determines the characteristic for the entire report year. If history datasets are available for a patient from multiple clinics, these are also aggregated according to the rules mentioned above into one dataset for the annual report.

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Map of participating CF facilities

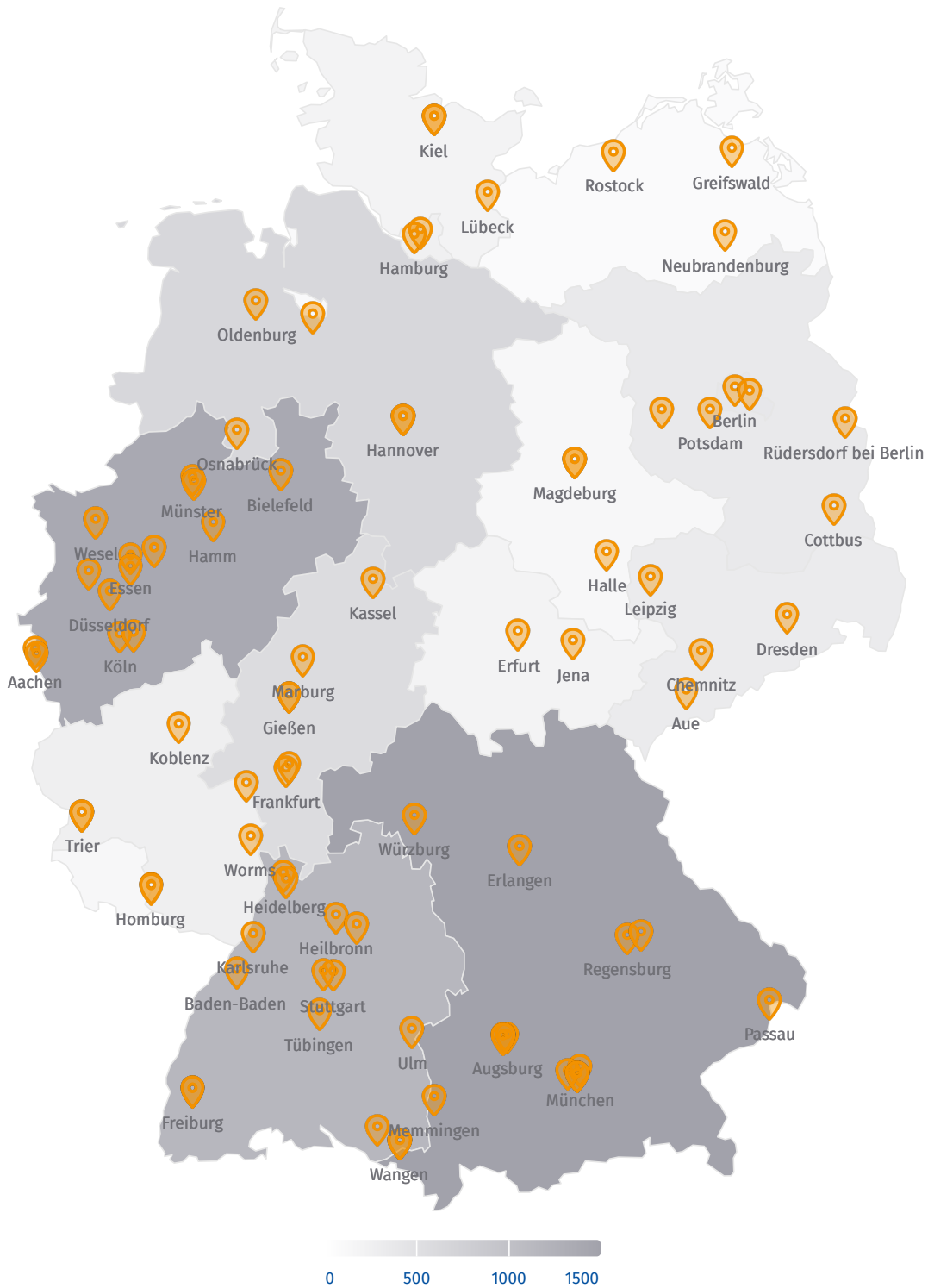


Fig. 1: Participating Cystic Fibrosis facilities 2024



The map shows all 83 CF facilities participating in the registry 2024. A list of all CF facilities and the reported patient numbers can be found on page 73. Write to us if your facility is not represented: mburkhart@muko.info

Addresses of the CF facilities can be found at: www.muko.info/leben-mit-cf/adressen

Distribution of patients

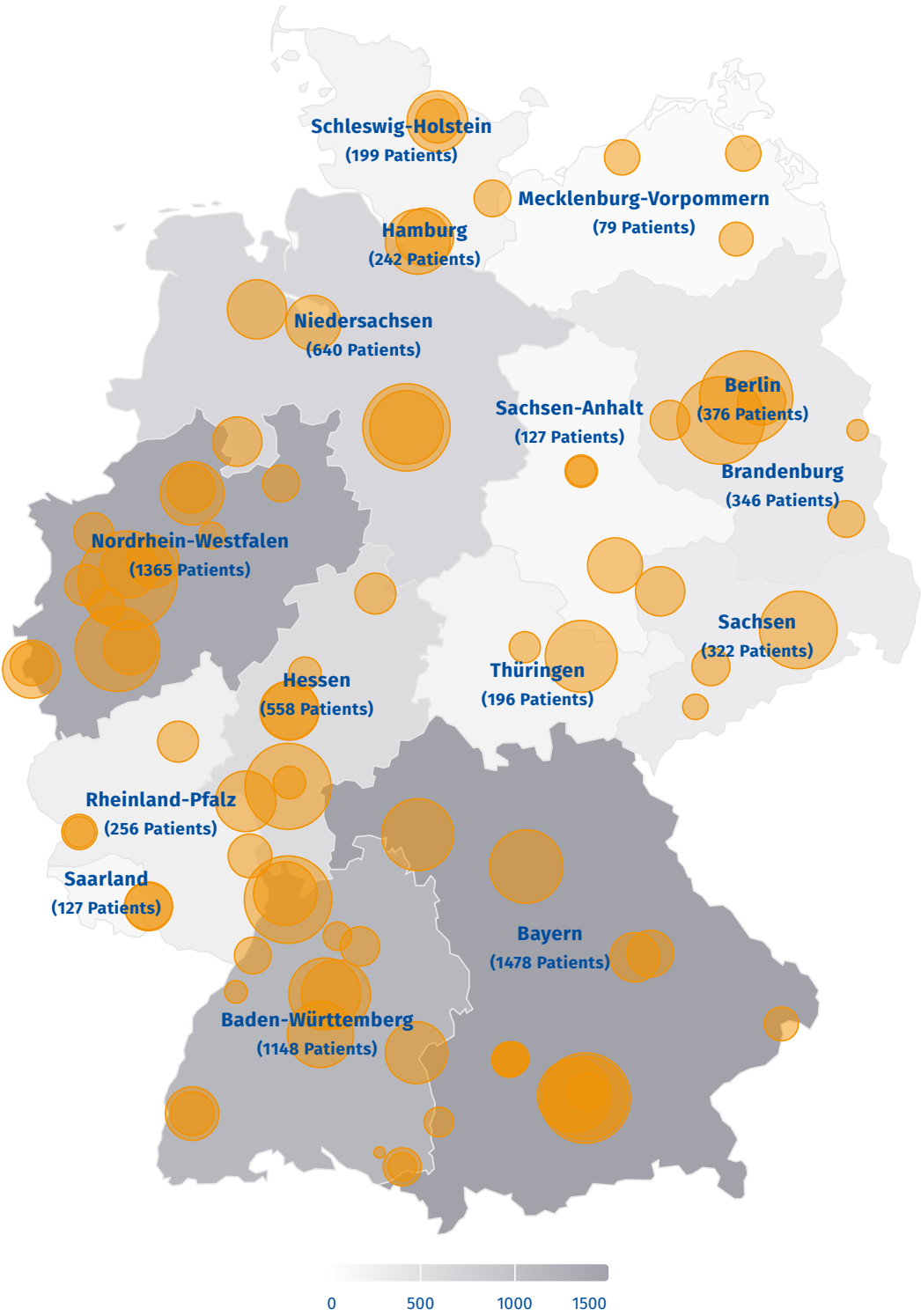


Fig. 2: Distribution of patients 2024



The assignment of patients to federal states is based on the postal code of the facility.

The map shows the patient numbers per federal state and the size (measured by the number of patients) of the clinics via the diameter of the circles.

01

Quick Overview

YEAR	2000	2005	2010	2015	2020	2023	2024
Number of participating facilities	78	83	81	89	88	85	83
Living patients ^{1 2}	4.275	5.195	5.891	6.647	7.420	7.660	7.776
Living patients with transplantations	63	169	286	454	563	453	438
Participating patients with history data	3.611	4.696	5.095	5.752	6.627	7.177	7.369
of which transplanted	30	109	195	295	365	344	341
Age in years (median)	14	16	18	20	21	23	23
Proportion of adults (≥ 18 years) in %	36,1	45,8	51,2	56,8	58,7	61,0	62,1
Male patients in % ¹	52,5	52,1	51,9	52,0	52,0	51,8	51,6
New diagnoses in the reporting year ¹	229	209	221	232	239	181	168
Age at new diagnosis in years (median)	1,2	0,9	1,0	0,7	0,2	0,1	0,1
of which diagnosis through newborn screening in %	0,4	1,0	2,7	10,8	56,9	61,3	66,7
Motherhood in the reporting year ¹	4	8	13	20	34	69	52
Fatherhood in the reporting year ¹	1	0	7	6	17	17	10
Deaths in the reporting year ¹	39	68	75	100	61	35	40
Deaths: % of all patients	1,1	1,4	1,5	1,7	0,9	0,5	0,5
Age at death in years (median)	22,3	26,1	28,9	32,1	35,9	39,8	43,2
(25th – 75th percentile)	(17 - 29)	(20 - 35)	(24 - 37)	(25 - 37)	(28 - 46)	(29 - 46)	(32 - 54)
Transplantations ¹	9	36	33	36	33	5	7
Transplantations lung ³	7	32	29	32	29	4	4
Transplantations liver ³	2	3	4	7	5	2	3
Kidney transplantations ³	0	1	1	0	1	0	0
Pancreas transplantations ³	0	0	0	1	0	0	0

Table 1: Quick overview of people with CF with history data, valid declaration of consent and Cystic Fibrosis diagnosis in the report years 2000 – 2024 in Germany

¹ Information on living patients, new diagnoses, deaths and transplanted patients as well as motherhoods and fatherhoods also includes patients without history data.

² As a result of the anonymization of patient data at the end of 2021, the number of living patients mentioned here will decrease in the following years, as it is no longer possible to determine the living status for anonymized patients.

³ Multiple mentions possible

Development of patient numbers

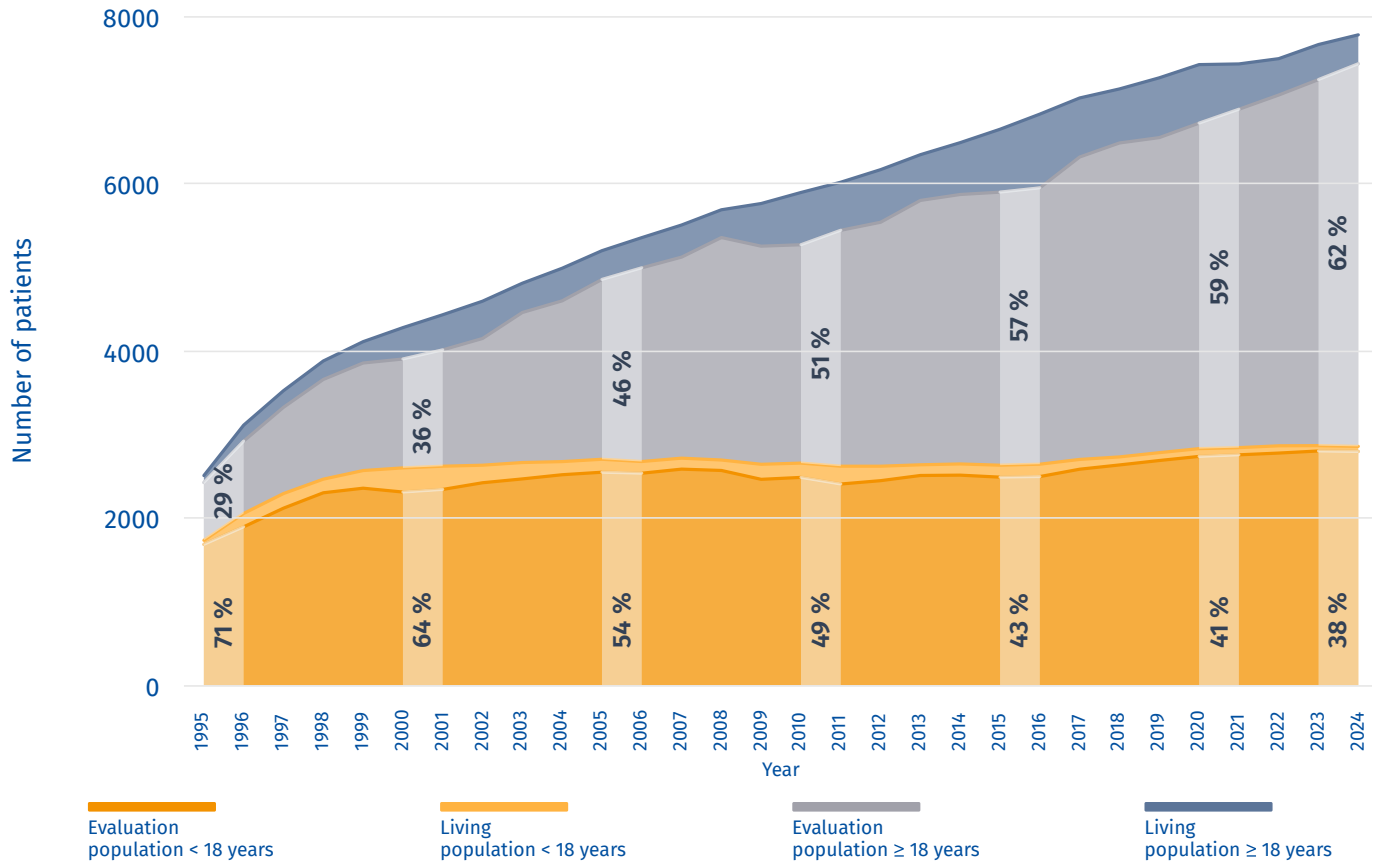


Fig. 3: Number of patients documented in the registry 1995 – 2024

YEAR	ANALYSIS-POPULATION	PERCENTAGE SHARE	LIVING-POPULATION
2024	7.369	95 %	7.776
2023	7.177	94 %	7.660
2022	6.969	93 %	7.491
2021	6.800	92 %	7.428
2020	6.627	89 %	7.420
2019	6.453	89 %	7.262
2018	6.387	90 %	7.129
2017	6.198	88 %	7.021
2016	5.798	85 %	6.828
2015	5.752	87 %	6.647
2014	5.733	88 %	6.487
2013	5.668	89 %	6.343
2012	5.362	87 %	6.164

YEAR	ANALYSIS-POPULATION	PERCENTAGE SHARE	LIVING-POPULATION
2011	5.226	87 %	6.014
2010	5.095	86 %	5.891
2009	5.069	88 %	5.759
2008	5.227	92 %	5.684
2007	4.987	91 %	5.502
2006	4.850	91 %	5.351
2005	4.696	90 %	5.195
2004	4.438	89 %	4.985
2003	4.260	89 %	4.806
2002	3.935	86 %	4.591
2001	3.731	84 %	4.429
2000	3.611	84 %	4.275

Table 2: Number of patients documented in the registry 2000 – 2024

Development of patient numbers

YEAR	EVALUATION POPULATION					LIVING POPULATION				
	TOTAL	< 18 YEARS	PERCENTAGE	≥ 18 YEARS	PERCENTAGE	TOTAL	< 18 YEARS	PERCENTAGE	≥ 18 YEARS	PERCENTAGE
2024	7.369	2.794	38 %	4.575	62 %	7.776	2.855	37 %	4.921	63 %
2023	7.177	2.800	39 %	4.377	61 %	7.660	2.864	37 %	4.796	63 %
2022	6.969	2.775	40 %	4.194	60 %	7.491	2.862	38 %	4.629	62 %
2021	6.800	2.754	41 %	4.046	59 %	7.428	2.840	38 %	4.588	62 %
2020	6.627	2.735	41 %	3.892	59 %	7.420	2.828	38 %	4.592	62 %
2019	6.453	2.686	42 %	3.767	58 %	7.262	2.780	38 %	4.482	62 %
2018	6.387	2.633	41 %	3.754	59 %	7.129	2.729	38 %	4.400	62 %
2017	6.198	2.582	42 %	3.616	58 %	7.021	2.699	38 %	4.322	62 %
2016	5.798	2.494	43 %	3.304	57 %	6.828	2.642	39 %	4.186	61 %
2015	5.752	2.487	43 %	3.265	57 %	6.647	2.630	40 %	4.017	60 %
2014	5.733	2.511	44 %	3.222	56 %	6.487	2.645	41 %	3.842	59 %
2013	5.668	2.507	44 %	3.161	56 %	6.343	2.635	42 %	3.708	58 %
2012	5.362	2.445	46 %	2.917	54 %	6.164	2.618	42 %	3.546	58 %
2011	5.226	2.405	46 %	2.821	54 %	6.014	2.618	44 %	3.396	56 %
2010	5.095	2.484	49 %	2.611	51 %	5.891	2.655	45 %	3.236	55 %
2009	5.069	2.461	49 %	2.608	51 %	5.759	2.641	46 %	3.118	54 %
2008	5.227	2.567	49 %	2.660	51 %	5.684	2.692	47 %	2.992	53 %
2007	4.987	2.583	52 %	2.404	48 %	5.502	2.714	49 %	2.788	51 %
2006	4.850	2.534	52 %	2.316	48 %	5.351	2.674	50 %	2.677	50 %
2005	4.696	2.546	54 %	2.150	46 %	5.195	2.701	52 %	2.494	48 %
2004	4.438	2.516	57 %	1.922	43 %	4.985	2.673	54 %	2.312	46 %
2003	4.260	2.466	58 %	1.794	42 %	4.806	2.662	55 %	2.144	45 %
2002	3.935	2.420	61 %	1.515	39 %	4.591	2.630	57 %	1.961	43 %
2001	3.731	2.340	63 %	1.391	37 %	4.429	2.618	59 %	1.811	41 %
2000	3.611	2.309	64 %	1.302	36 %	4.275	2.598	61 %	1.677	39 %
1999	3.641	2.355	65 %	1.286	35 %	4.107	2.566	62 %	1.541	38 %
1998	3.492	2.300	66 %	1.192	34 %	3.876	2.463	64 %	1.413	36 %
1997	3.147	2.116	67 %	1.031	33 %	3.521	2.291	65 %	1.230	35 %
1996	2.758	1.893	69 %	865	31 %	3.109	2.053	66 %	1.056	34 %
1995	2.374	1.683	71 %	691	29 %	2.506	1.732	69 %	774	31 %

Table 3: Development of age distribution (< 18 vs. ≥ 18 years) for the years 1995 – 2024

Age structure

All 7.369 patients with history data 2024 are included in the age structure calculations. The age of patients not documented as deceased as well as deceased patients without a date of death was calculated in completed years at the end of the respective report year. If a date of death was available, the age at the time of death was calculated in completed years.

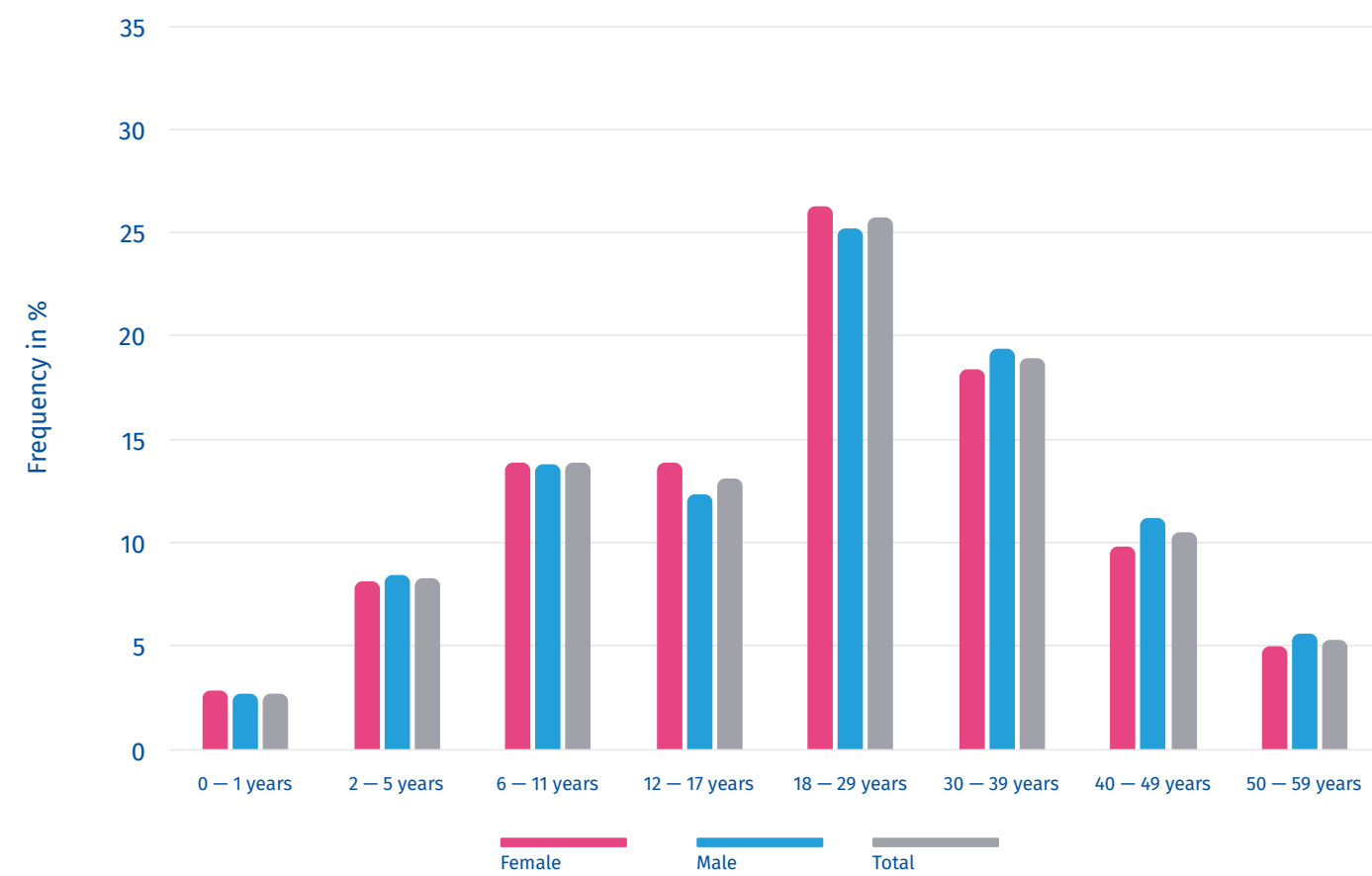


Fig. 4: Age distribution of people with CF 2024

	FEMALE	MALE	TOTAL
Number	3.568	3.801	7.369
Average (years)	24,1	24,8	24,4
Median (years)	23	24	23
Minimum (years)	0	0	0
Maximum (years)	87	86	87
25th percentile (years)	12	12	12
75th percentile (years)	34	36	35
Number < 18 years	1.382	1.412	2.794
Number ≥ 18 years	2.186	2.389	4.575

Table 4: Age distribution of people with CF 2024

Age structure

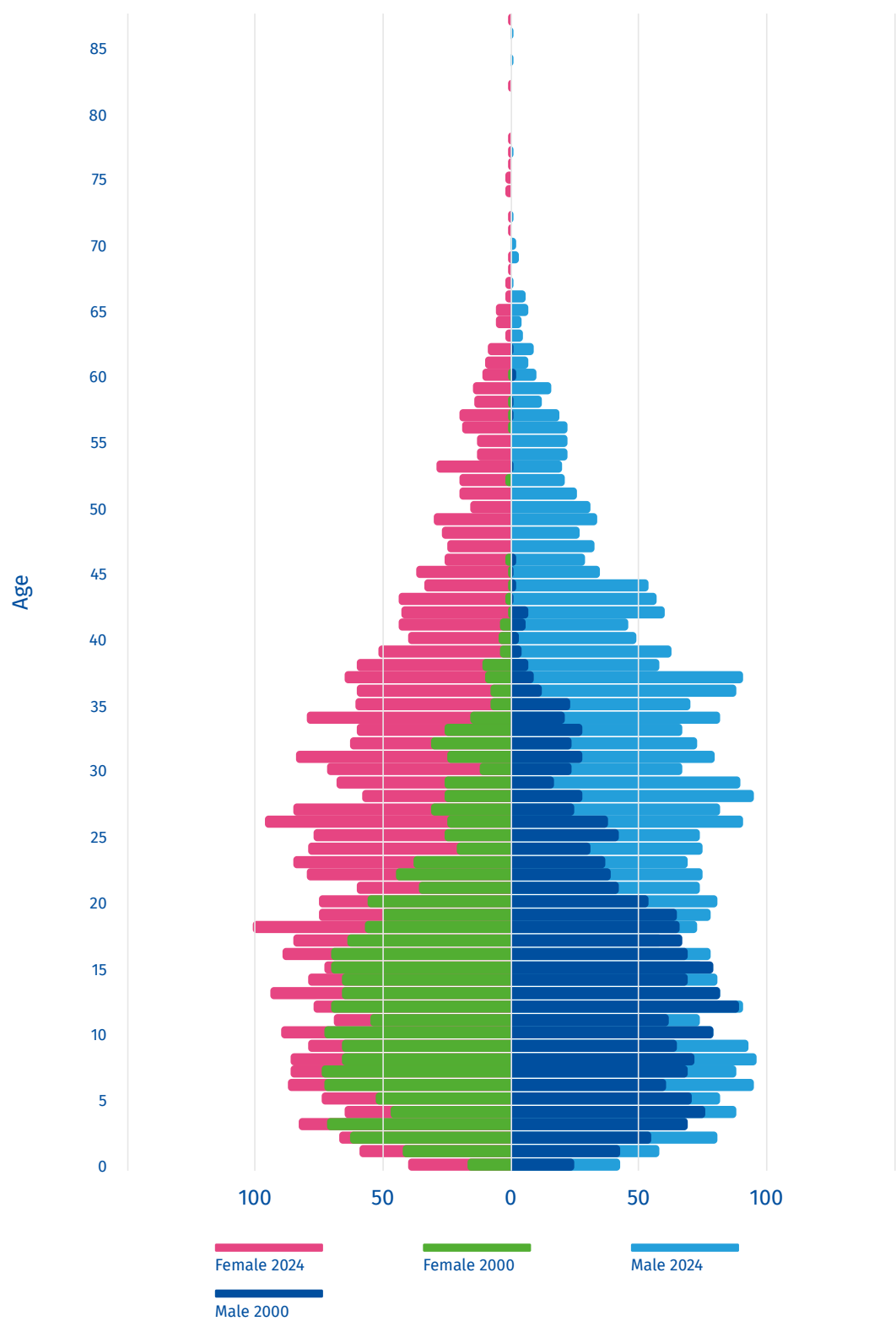


Fig. 5: Age pyramid of people with CF 2000 vs. 2024

Cystic fibrosis diagnosis

4a. Diagnoses in 2024

In year 2024, 168 patients were diagnosed, for 125 patients (75.9 %) history data are available. The age distribution of all 2024 newly diagnosed patients is shown in the following tables.

There was one patient born in year 2024 where a date of new diagnosis is missing.

	NUMBER	AVERAGE	MEDIAN	MINIMUM	MAXIMUM	25TH PERCENTILE	75TH PERCENTILE	MISSING
Age in years	167	5,9	0,1	0	68,3	0,0	3,9	1

Table 5: Age at diagnosis of all people with CF diagnosed in year 2024 (168)

Newborn screening was performed in 112 (66.7 %) of the people with CF diagnosed in 2024. One patient (12.7 %) had a meconium ileus. The age at diagnosis of the 2024 patients newly diagnosed via newborn screening is as follows:

	NUMBER	AVERAGE	MEDIAN	MINIMUM	MAXIMUM	25TH PERCENTILE	75TH PERCENTILE	MISSING
Age in days	111	63,9	30,0	0	1.542	19,5	44,0	1

Table 6: Age at diagnosis of all people with CF diagnosed in year 2024 via newborn screening (112)

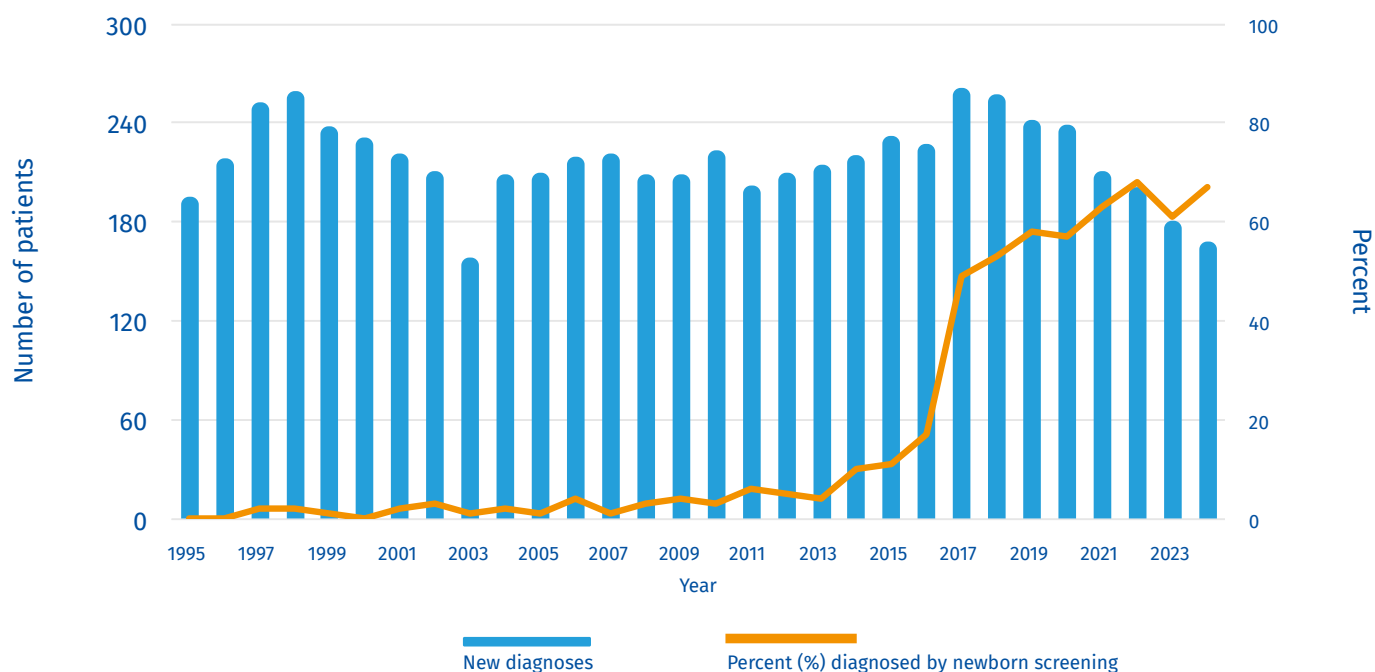


Fig. 6: Number of new diagnoses and percentage frequency of people with CF diagnosed by newborn screening 1995 – 2024

Cystic fibrosis diagnosis

4b. Age at diagnosis (Status 2024)

The distribution of age at diagnosis of the 7.369 patients with history data 2024 is shown in the following figures and tables. For 232 patients (3.1 %), no information on the diagnosis date was available.

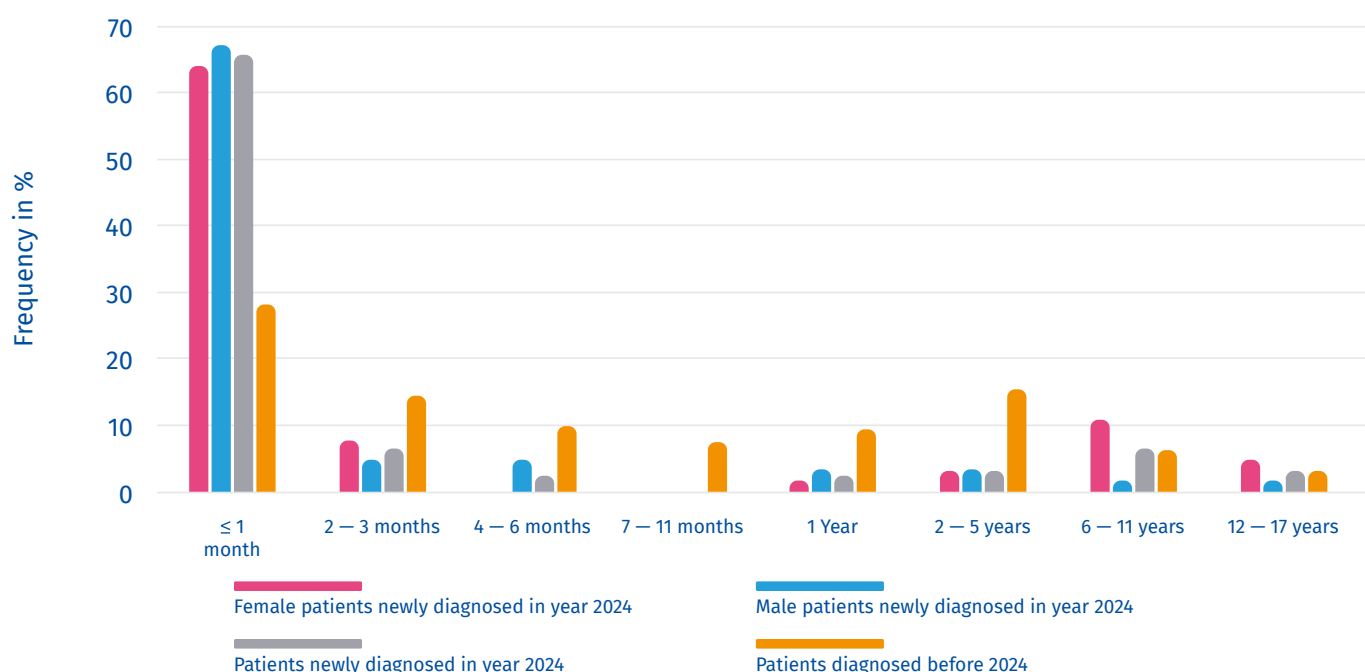


Fig. 7: Age-related frequencies in diagnosed people with CF

AGE	TOTAL IN 2024			TOTAL BEFORE 2024		
	FREQUENCY	PERCENT	ACCUMULATED	FREQUENCY	PERCENT	ACCUMULATED
≤ 1 month	82	65,6	65,6	1.967	28,1	28,1
2 – 3 months	8	6,4	72,0	1.008	14,4	42,5
4 – 6 months	3	2,4	74,4	691	9,9	52,4
7 – 11 months	0	0,0	74,4	526	7,5	59,9
1 Year	3	2,4	76,8	663	9,5	69,4
2 – 5 years	4	3,2	80,0	1.090	15,5	84,9
6 – 11 years	8	6,4	86,4	436	6,2	91,1
12 –17 years	4	3,2	89,6	226	3,2	94,3
≥ 18 years	13	10,4	100,0	405	5,8	100,0
Total	125	-	-	7.012	-	-
Missing	0	0,0	-	232	3,3	-

Table 7: Age at diagnosis in diagnosed people with CF

Cystic fibrosis diagnosis

4c. Genotyping

Genotyping was available for 7.369 patients (99,3 %). Missing information was treated as "mutation not identified" in the following representation.

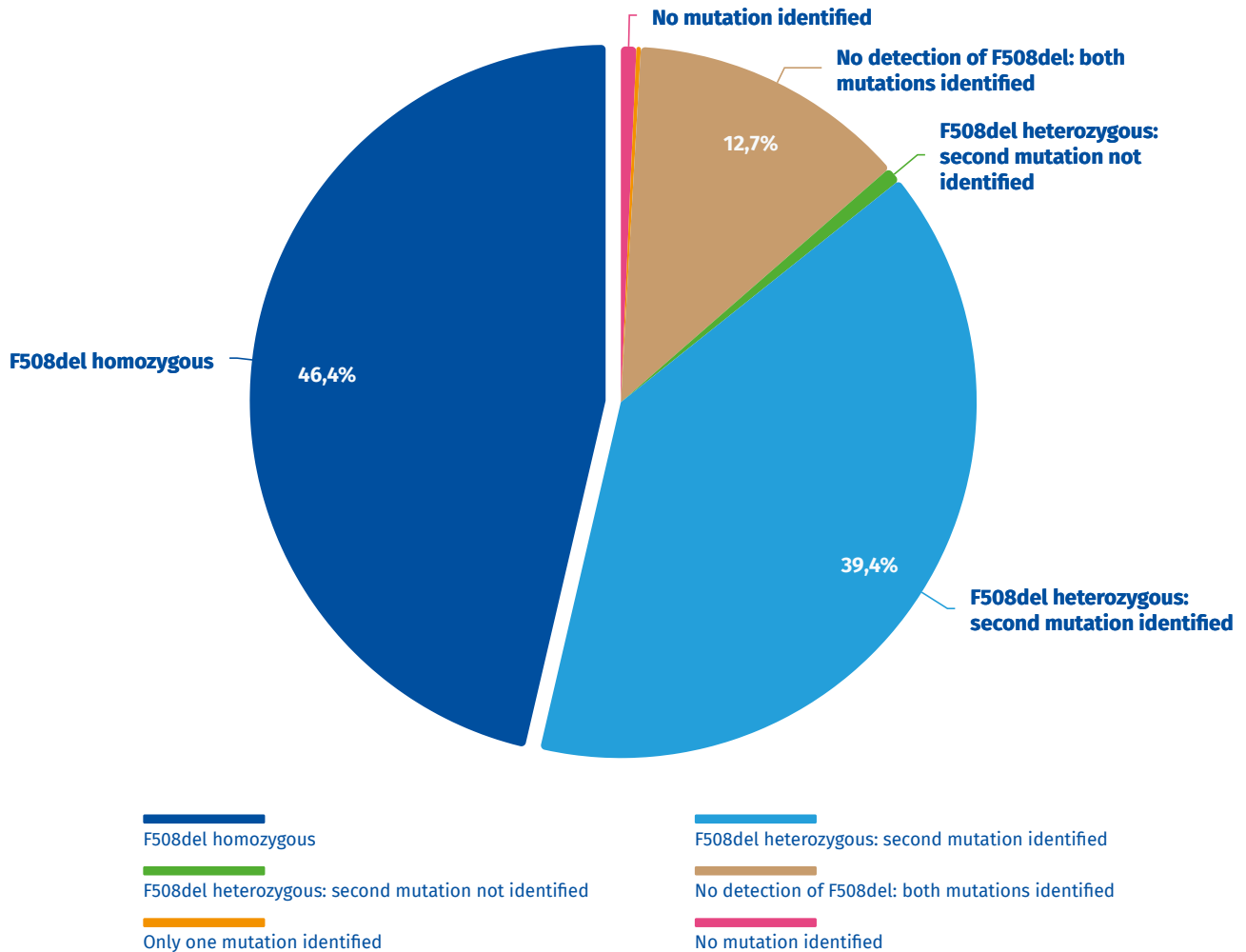


Fig. 8: Mutation combinations of people with CF 2024

MUTATION COMBINATIONS	FREQUENCY	PERCENT
F508del homozygous	3.419	46,4
F508del heterozygous: second mutation identified	2.902	39,4
F508del heterozygous: second mutation not identified	48	0,7
No detection of F508del: both mutations identified	933	12,7
Only one mutation identified	17	0,2
No mutation identified	50	0,7
Total	7.369	100,0

Table 8: Mutation combinations of people with CF 2024

Cystic fibrosis diagnosis

4c. Genotyping

The frequencies for the individual alleles are shown below, with only those with a relative frequency of at least 0.4% shown individually.

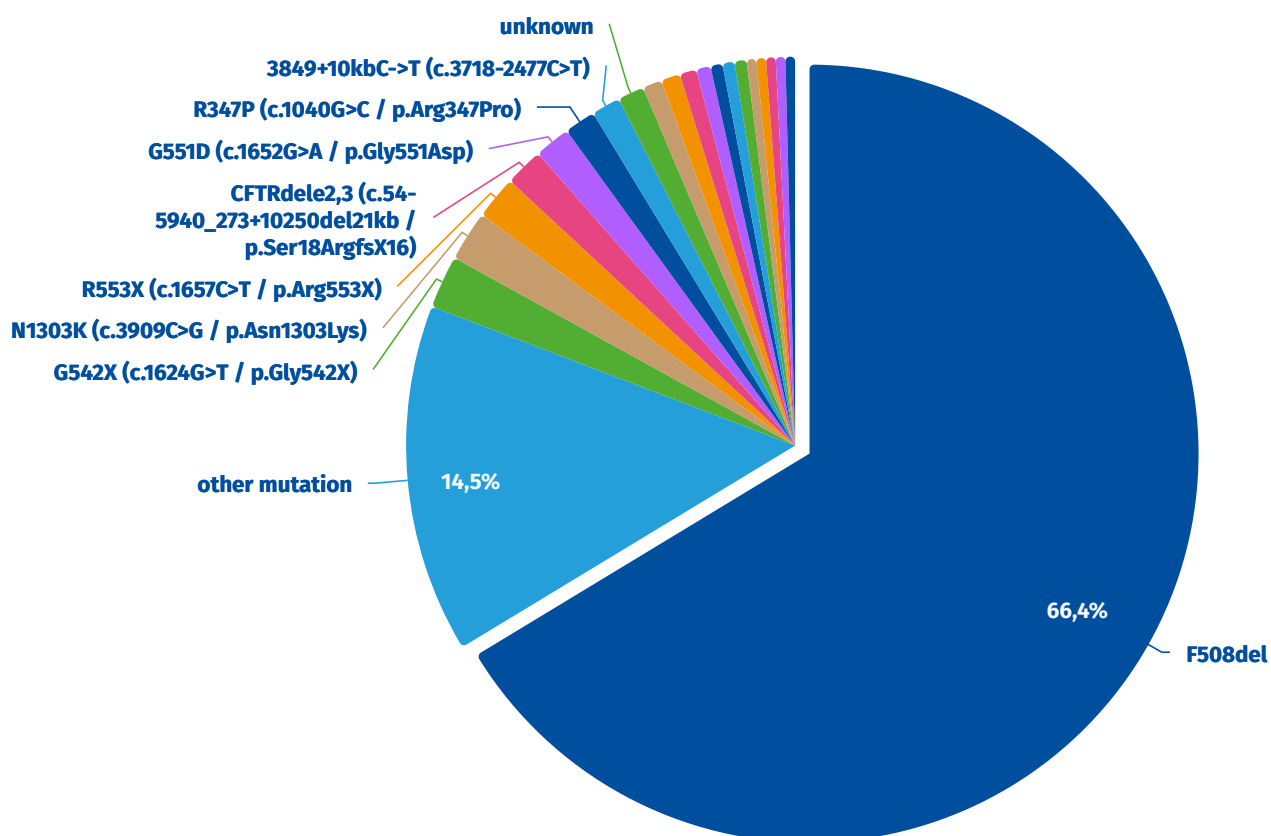


Fig. 9: CFTR genotyping of people with CF 2024

Cystic fibrosis diagnosis

4c. Genotyping

FIRST AND SECOND MUTATION	FREQUENCY	PERCENT
F508del (c.1521_1523delCTT / p.Phe508del)	9.788	66,4
G542X (c.1624G>T / p.Gly542X)	317	2,2
N1303K (c.3909C>G / p.Asn1303Lys)	305	2,1
R553X (c.1657C>T / p.Arg553X)	260	1,8
CFTRdele2,3 (c.54-5940_273+10250del21kb / p.Ser18ArgfsX16)	231	1,6
G551D (c.1652G>A / p.Gly551Asp)	222	1,5
R347P (c.1040G>C / p.Arg347Pro)	197	1,3
3849+10kbC->T (c.3718-2477C>T)	170	1,2
2789+5G->A (c.2657+5G>A)	122	0,8
1717-1G->A (c.1585-1G>A)	121	0,8
W1282X (c.3846G>A / p.Trp1282X)	100	0,7
2183AA->G (c.2051_2052delAAinsG / p.Lys684SerfsX38)	89	0,6
2184insA (c.2052dupA or c.2052dup / p.Gln685ThrfsX4 or p.Gln685Thrfs*4)	80	0,5
3272-26A->G (c.3140-26A>G)	76	0,5
I336K (c.1007T>A / p.Ile336Lys)	67	0,5
M1101K (c.3302T>A / p.Met1101Lys)	65	0,4
1677delTA (c.1545_1546delTA / p.Tyr515X)	60	0,4
R1162X (c.3484C>T / p.Arg1162X)	59	0,4
621+1G->T (c.489+1G>T)	56	0,4
G85E (c.254G>A / p.Gly85Glu)	54	0,4
other mutation	2.134	14,5
unknown	165	1,1
Total	14.738	100,0

Table 9: CFTR genotyping of people with CF 2024

Nutritional Status

5a. Children and adolescents under 18 years

5a.i Median BMI Percentile

Included were all patients from 2 – 17 years without transplantation with history data 2024 (n=2645). For 4 patients (0,15 %) no information on nutritional status was available. KiGGS BMI percentiles were used to assess nutritional status in children and adolescents. Age was calculated at the time of physical examination.

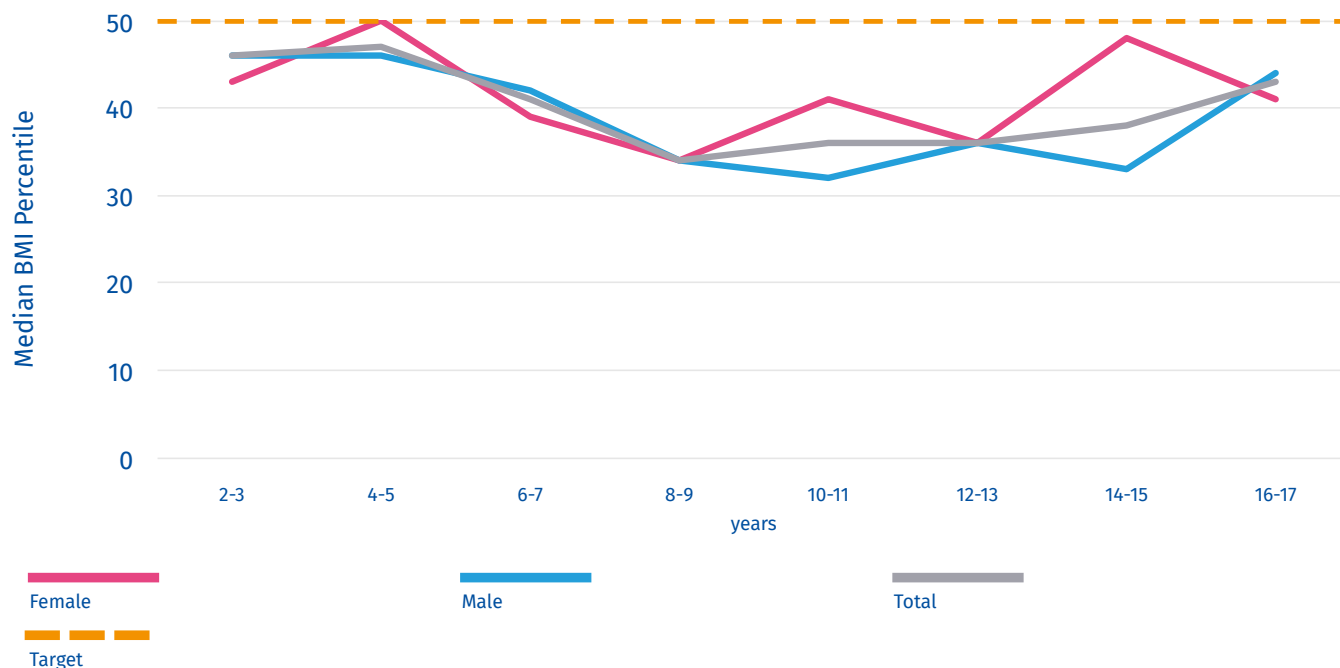


Fig. 10: Median BMI percentiles of children and adolescents between 2 – 17 years 2024. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

AGE	FEMALE			MALE			TOTAL		
	NUMBER	MEDIAN	25TH – 75TH PERCENTILE	NUMBER	MEDIAN	25TH – 75TH PERCENTILE	NUMBER	MEDIAN	25TH – 75TH PERCENTILE
2-3 years	150	43,0	22,0 – 65,0	162	46,0	22,0 – 71,0	312	46,0	22,0 – 69,0
4-5 years	164	50,0	23,5 – 69,0	180	46,0	21,8 – 74,0	344	47,0	22,0 – 71,0
6-7 years	190	39,0	18,3 – 65,0	190	42,0	18,0 – 63,0	380	41,0	18,0 – 63,5
8-9 years	165	34,0	19,0 – 60,0	182	34,0	17,0 – 58,0	347	34,0	18,0 – 58,0
10-11 years	148	41,0	17,8 – 62,3	169	32,0	14,0 – 56,0	317	36,0	16,0 – 60,0
12-13 years	178	36,0	18,0 – 61,0	155	36,0	15,0 – 61,0	333	36,0	17,0 – 61,0
14-15 years	145	48,0	22,0 – 68,0	161	33,0	17,0 – 55,0	306	38,0	19,0 – 62,0
16-17 years	178	41,0	16,0 – 62,0	124	44,0	23,0 – 67,0	302	43,0	18,0 – 64,0
Total	1.318	40,0	19,0 – 64,0	1.323	39,0	18,0 – 63,0	2.641	40,0	18,0 – 64,0

Table 10: BMI percentiles of children and adolescents from 2 – 17 years 2024. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

Nutritional Status

5a. Children and adolescents under 18 years

5a.ii Weight categories

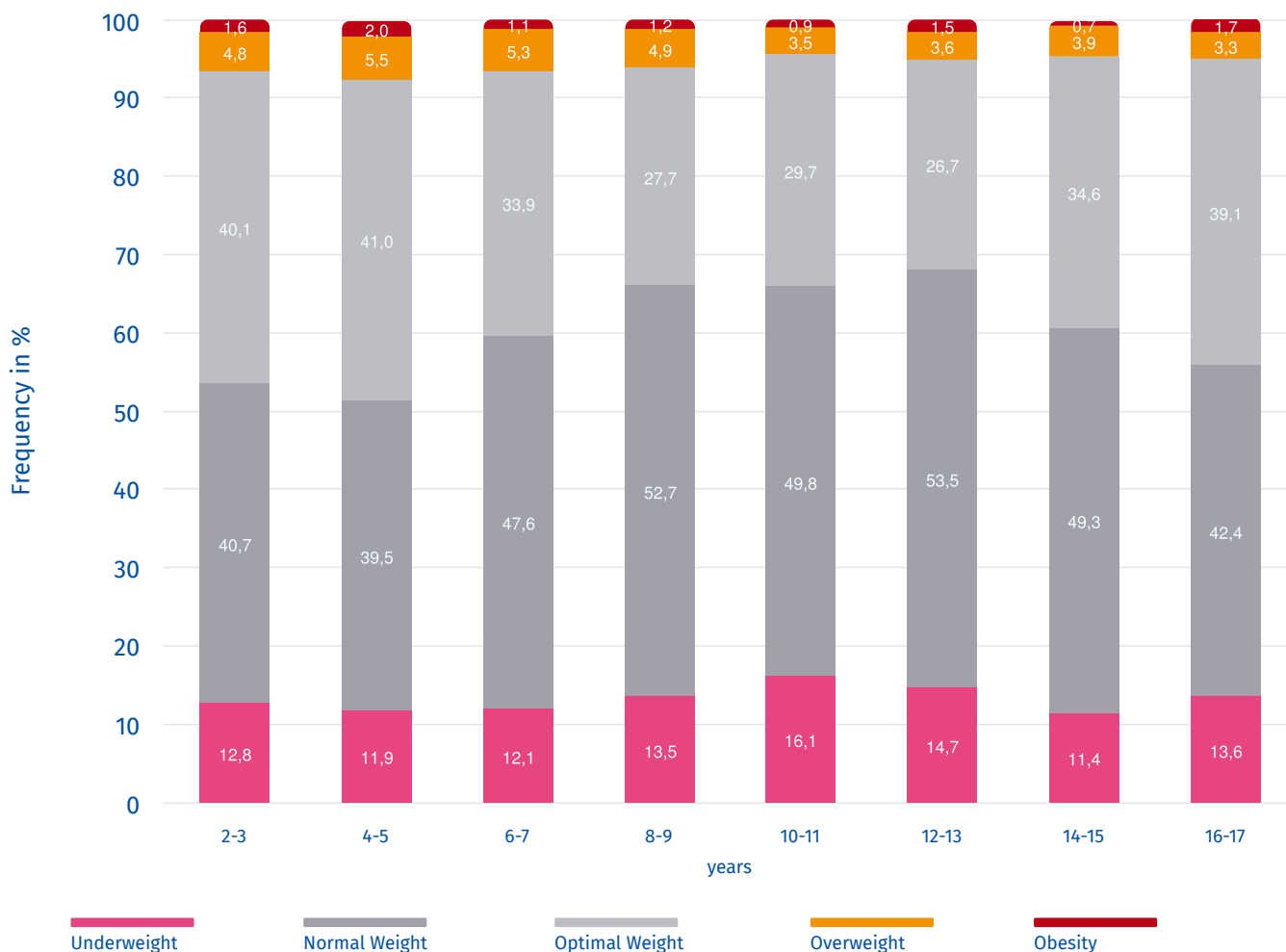


Fig. 11: Weight categories of children and adolescents between 2 – 17 years 2024, underweight: BMI percentile < 10, normal weight: BMI percentile 10 – 49, optimal weight: BMI percentile 50 – 89, overweight: BMI percentile 90 – 96, obesity: BMI percentile ≥ 97. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

BMI PERCENTILES KIGGS	FEMALE	MALE	TOTAL
Underweight 2024	13,1	13,5	13,3
Normal weight 2024	45,4	48,6	47,0
Optimal weight 2024	36,6	31,4	34,0
Overweight 2024	4,2	4,5	4,4
Obesity 2024	0,7	2,0	1,3

Table 11: Weight categories of children and adolescents between 2 – 17 years (frequencies in %) 2024, underweight: BMI percentile < 10, normal weight: BMI percentile 10 – 49, optimal weight: BMI percentile 50 – 89, overweight: BMI percentile 90 – 96, obesity: BMI percentile ≥ 97. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

Nutritional Status

5a. Children and adolescents under 18 years

5a.iii Length target weight

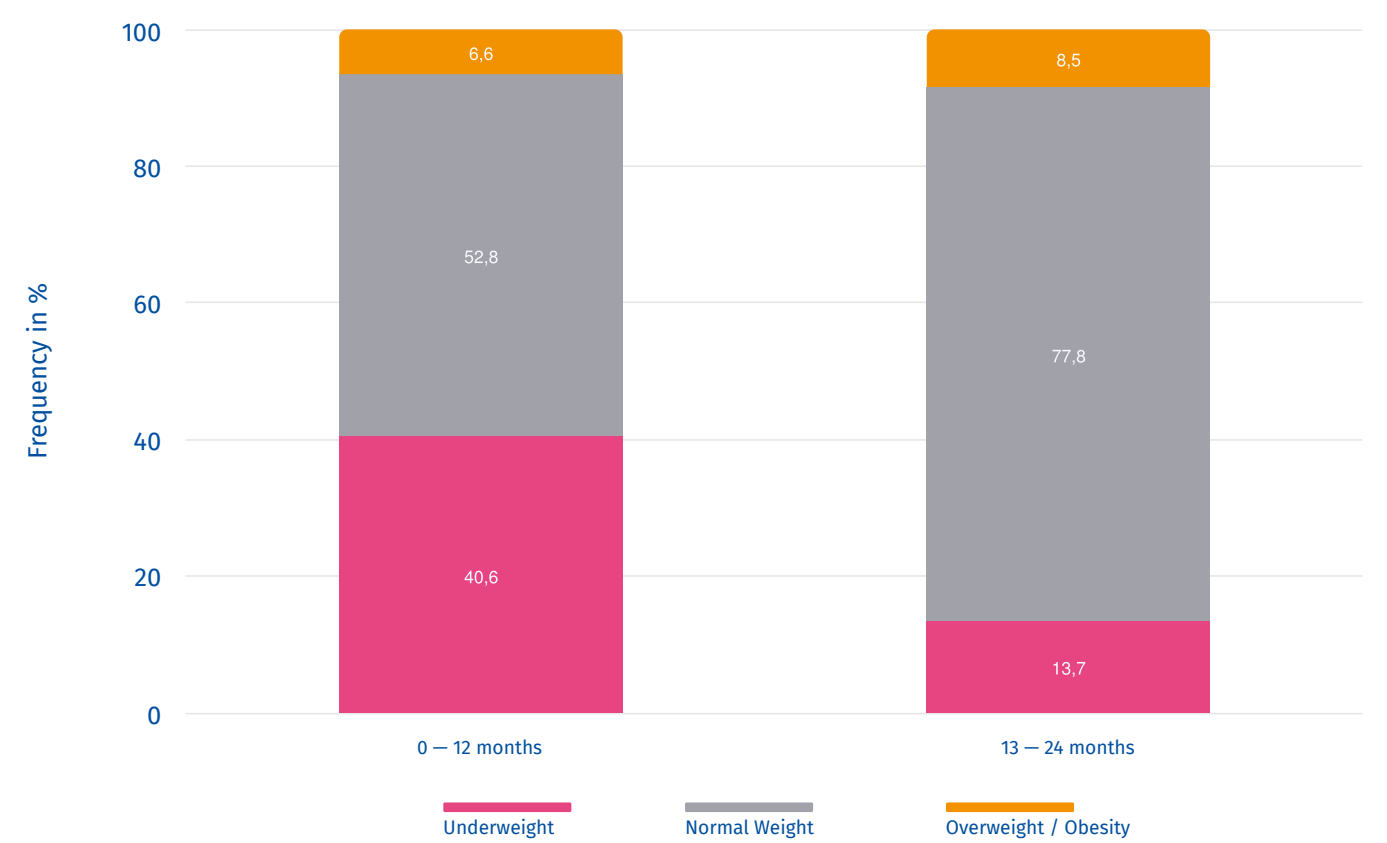


Fig. 12: Weight categories of children under 2 years (frequencies in %) according to length/target weight (LSG) 2024 Underweight: LSG <90 %; normal weight: LSG 90 – 110 %; overweight/obesity: LSG >110 %. Until 2014, birthday-near LSG was recorded, from 2014 LSG at the time of recording the best lung function of the calendar year.

LENGTH TARGET WEIGHT	FEMALE		MALE		TOTAL	
	0 – 12 MONTHS	13 – 24 MONTHS	0 – 12 MONTHS	13 – 24 MONTHS	0 – 12 MONTHS	13 – 24 MONTHS
Underweight	48,1	14,3	33,3	13,1	40,6	13,7
Normal weight	48,1	78,6	57,4	77,0	52,8	77,8
Overweight / Obesity	3,8	7,1	9,3	9,8	6,6	8,5

Table 12: Weight categories of children under 2 years (frequencies in %) according to length/target weight (LSG) 2024 Underweight: LSG <90 %; normal weight: LSG 90 – 110 %; overweight/obesity: LSG >110 %. Until 2014, birthday-near LSG was recorded, from 2014 LSG at the time of recording the best lung function of the calendar year.

Nutritional Status

5a. Children and adolescents under 18 years

5a.iv Development of nutritional status 2000 – 2024

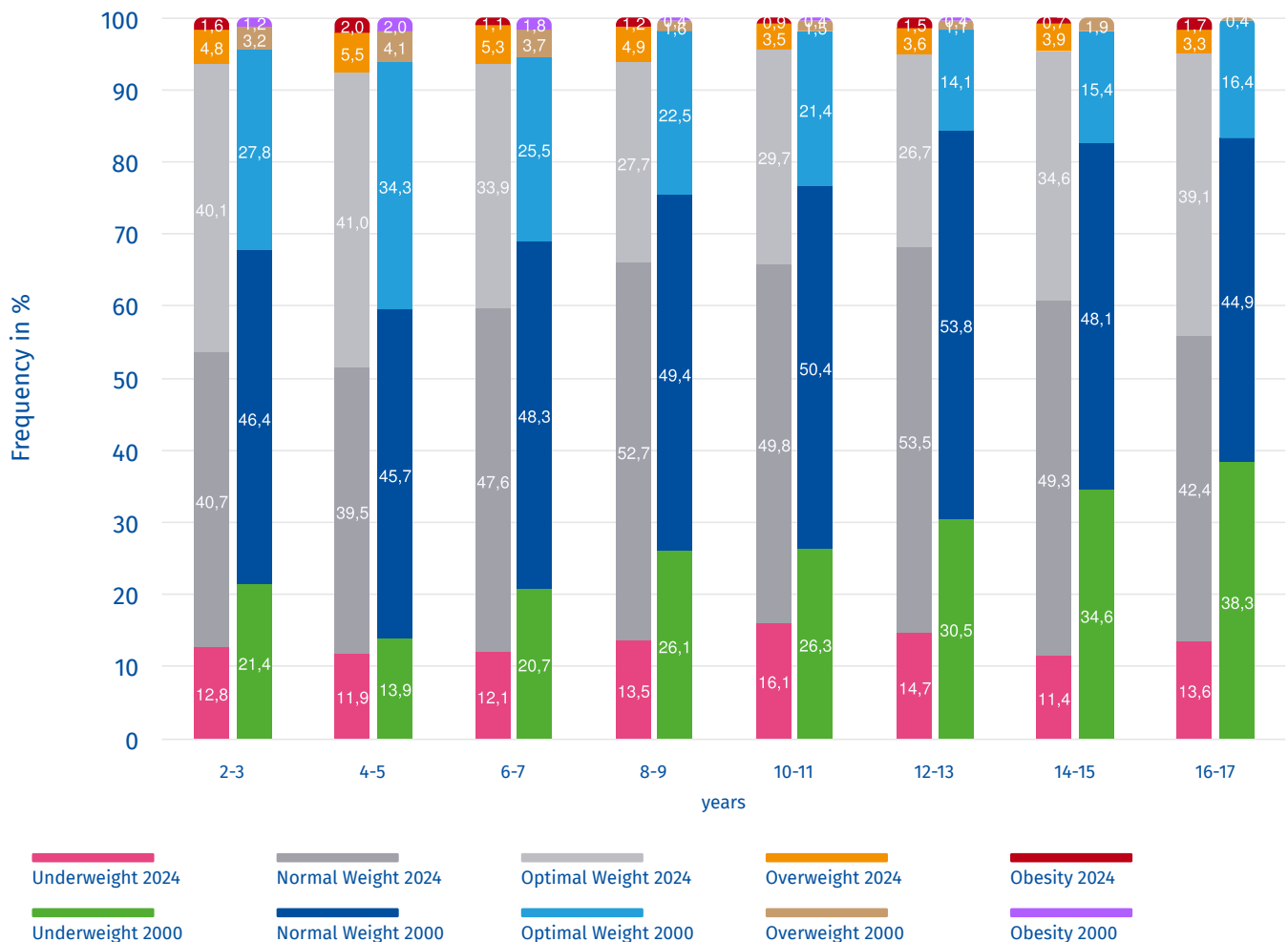


Fig. 13: Development of weight categories of children and adolescents up to 17 years (frequencies in %) 2000 – 2024, underweight: BMI percentile < 10; normal weight: BMI percentile 10 – 49; optimal weight: BMI percentile 50 – 89; overweight: BMI percentile 90 – 96, obesity: BMI percentile ≥ 97. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

Nutritional Status

5a. Children and adolescents under 18 years

5a.iv Development of nutritional status 2000 – 2024

YEAR	AGE IN YEARS							
	2 – 3	4 – 5	6 – 7	8 – 9	10 – 11	12 – 13	14 – 15	16 – 17
Underweight								
2000	21,4	13,9	20,7	26,1	26,3	30,5	34,6	38,3
2010	22,4	15,8	16,1	19,3	24,8	28,3	24,6	27,2
2020	11,6	12,8	12,7	12,8	18,5	20,4	15,0	20,5
2024	12,8	11,9	12,1	13,5	16,1	14,7	11,4	13,6
Normal weight								
2000	46,4	45,7	48,3	49,4	50,4	53,8	48,1	44,9
2010	35,8	50,4	51,1	54,8	58,7	49,8	47,1	53,0
2020	39,3	42,3	50,3	52,5	56,5	52,4	49,5	46,9
2024	40,7	39,5	47,6	52,7	49,8	53,5	49,3	42,4
Optimal weight								
2000	27,8	34,3	25,5	22,5	21,4	14,1	15,4	16,4
2010	35,8	29,1	30,9	23,7	14,8	20,4	26,4	17,4
2020	40,6	38,8	31,5	29,1	22,5	24,3	31,8	30,8
2024	40,1	41,0	33,9	27,7	29,7	26,7	34,6	39,1
Overweight								
2000	3,2	4,1	3,7	1,6	1,5	1,1	1,9	0,4
2010	5,0	3,6	0,9	1,5	1,3	0,9	1,8	2,0
2020	6,3	4,3	4,8	4,7	2,2	1,9	3,4	1,8
2024	4,8	5,5	5,3	4,9	3,5	3,6	3,9	3,3
Obesity								
2000	1,2	2,0	1,8	0,4	0,4	0,4	0,0	0,0
2010	1,0	1,1	0,9	0,7	0,3	0,6	0,0	0,3
2020	2,2	1,7	0,7	0,9	0,4	1,0	0,3	0,0
2024	1,6	2,0	1,1	1,2	0,9	1,5	0,7	1,7

Table 13: Development of weight categories of children and adolescents up to 17 years (frequencies in %) 2000 – 2024, underweight: BMI percentile < 10; normal weight: BMI percentile 10 – 49; optimal weight: BMI percentile 50 – 89; overweight: BMI percentile 90 – 96; obesity: BMI percentile ≥ 97. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

Nutritional Status

5a. Children and adolescents under 18 years

5a.v Median BMI percentile by birth cohort

Development of median BMI percentile of children and adolescents under 18 years by birth cohorts 1991 – 2020 for data from years 1996 – 2024. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

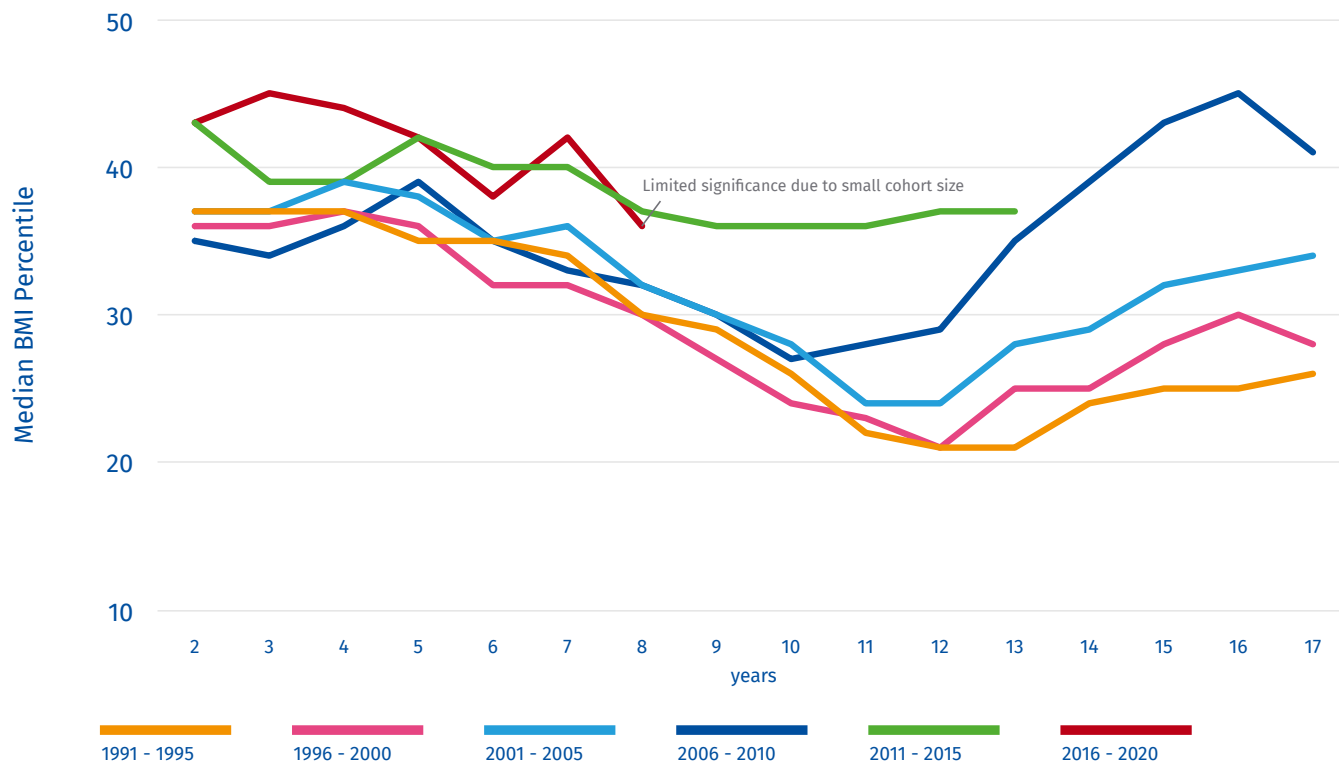


Fig. 14: Development of median BMI percentile of children and adolescents under 18 years by birth cohorts 1991 – 2020 for data from years 1996 – 2024. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

BIRTH COHORTS	AGE IN YEARS															
	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
1991 - 1995	37	37	37	35	35	34	30	29	26	22	21	21	24	25	25	26
1996 - 2000	36	36	37	36	32	32	30	27	24	23	21	25	25	28	30	28
2001 - 2005	37	37	39	38	35	36	32	30	28	24	24	28	29	32	33	34
2006 - 2010	35	34	36	39	35	33	32	30	27	28	29	35	39	43	45	41
2011 - 2015	43	39	39	42	40	40	37	36	36	36	37	37	-	-	-	-
2016 - 2020	43	45	44	42	38	42	36*	-	-	-	-	-	-	-	-	-

Table 14: Development of median BMI percentile of children and adolescents under 18 years by birth cohorts 1991 – 2020 for data from years 1996 – 2024. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

* Limited significance due to small cohort size

Nutritional Status

5b. Adults from 18 years

5b.i Median BMI

Included were adult patients without transplantation with history data 2024 (n=4149). For 26 patients (0,63 %) no information on nutritional status was available. Age was calculated at the time of physical examination.

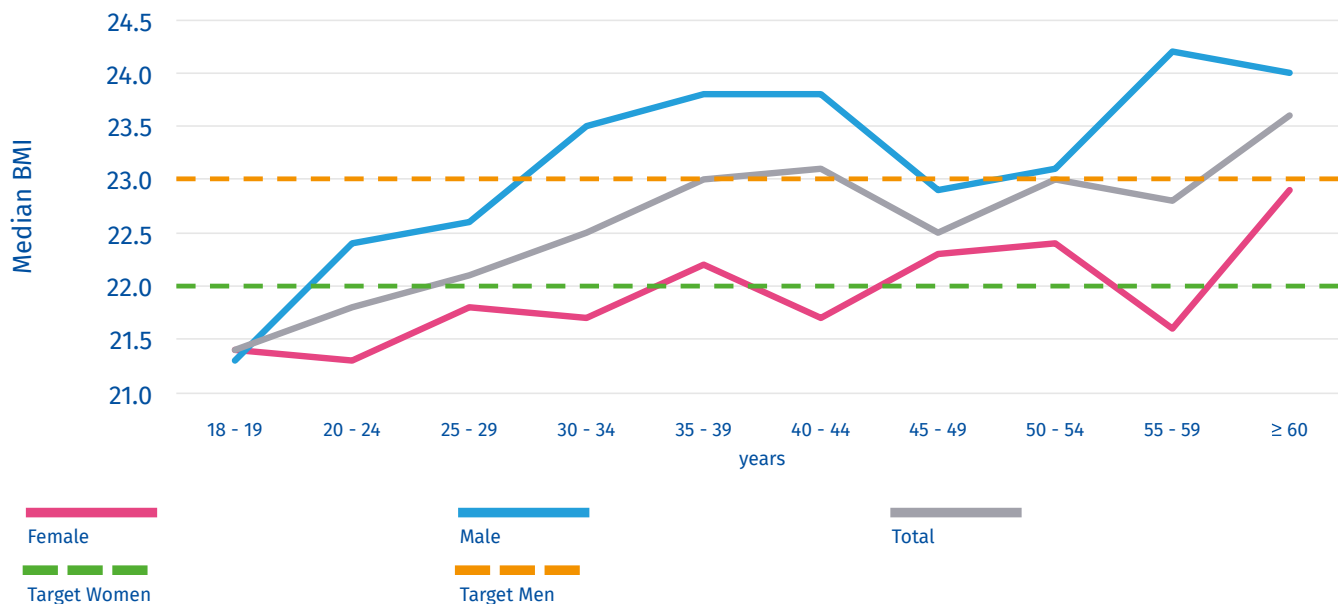


Fig. 15: Median BMI of adults aged 18 and over 2024. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

AGE	FEMALE			MALE			TOTAL		
	NUMBER	MEDIAN	25TH - 75TH PERCENTILE	NUMBER	MEDIAN	25TH - 75TH PERCENTILE	NUMBER	MEDIAN	25TH - 75TH PERCENTILE
18 - 19 years	160	21,4	19,7 - 23,8	151	21,3	19,7 - 23,2	311	21,4	19,7 - 23,4
20 - 24 years	368	21,3	19,7 - 23,4	350	22,4	20,1 - 24,6	718	21,8	19,9 - 24,0
25 - 29 years	350	21,8	19,7 - 23,9	400	22,6	20,5 - 25,7	750	22,1	20,1 - 24,7
30 - 34 years	325	21,7	20,0 - 24,2	347	23,5	21,6 - 25,5	672	22,5	20,7 - 24,8
35 - 39 years	250	22,2	20,3 - 24,8	325	23,8	21,6 - 25,7	575	23,0	21,0 - 25,4
40 - 44 years	179	21,7	20,0 - 24,1	236	23,8	21,8 - 25,7	415	23,1	20,9 - 25,5
45 - 49 years	112	22,3	20,3 - 24,2	138	22,9	21,0 - 25,4	250	22,5	20,6 - 25,1
50 - 54 years	85	22,4	21,0 - 25,1	103	23,1	21,8 - 25,2	188	23,0	21,2 - 25,2
55 - 59 years	71	21,6	20,6 - 23,8	72	24,2	22,3 - 26,2	143	22,8	21,1 - 25,6
≥ 60 years	50	22,9	20,3 - 27,4	51	24,0	21,4 - 26,8	101	23,6	20,5 - 26,9
Total	1.950	21,7	20,0 - 24,1	2.173	23,1	21,0 - 25,4	4.123	22,4	20,4 - 24,8

Table 15: BMI of adults aged 18 and over 2024. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

Nutritional Status

5b. Adults from 18 years

5b.ii Weight categories

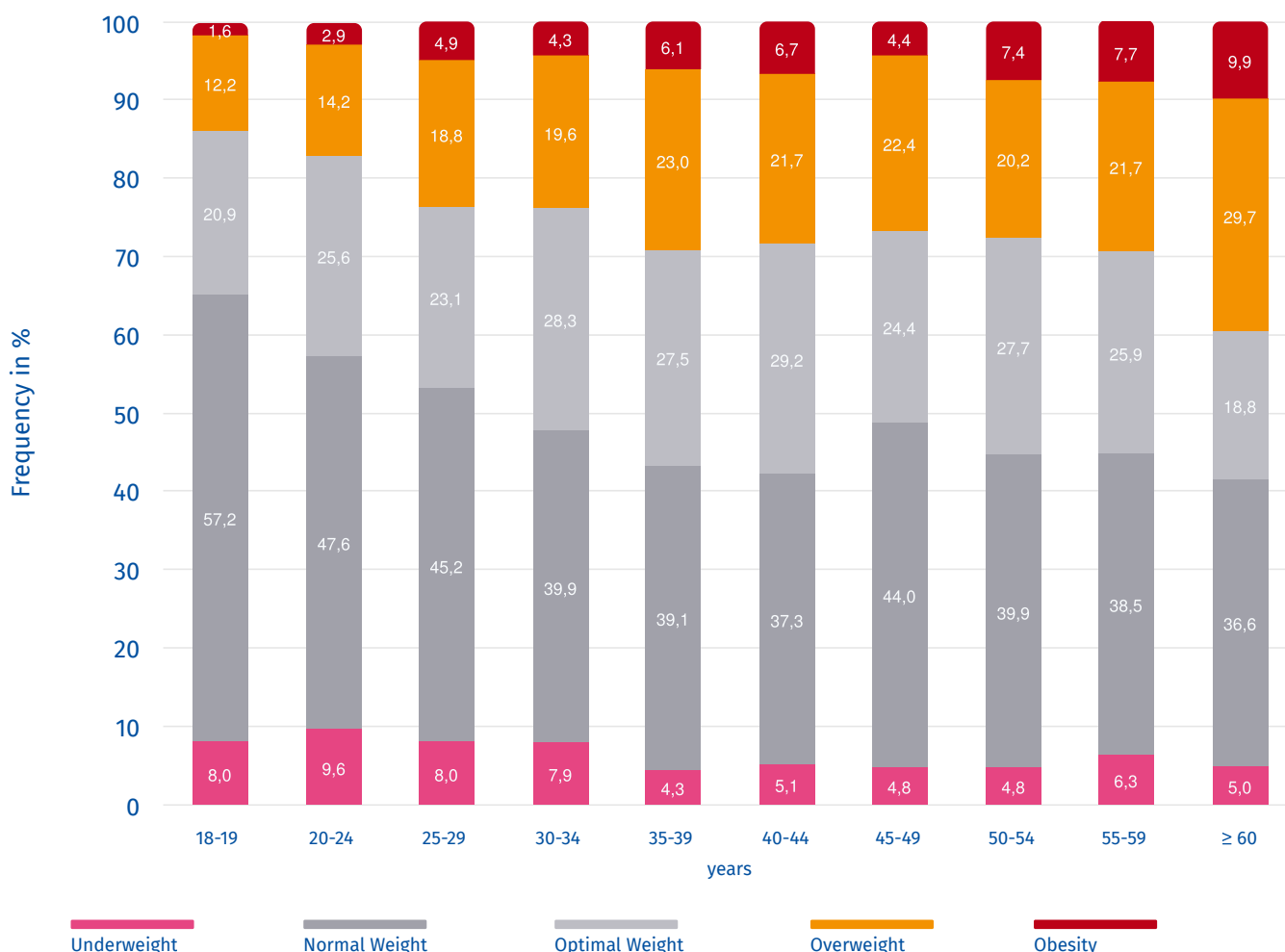


Fig. 16: Weight categories of adults aged 18 and over 2024, underweight: BMI < 18.5 kg/sqm; normal weight: BMI men 18.5 – 22.9 kg/sqm; BMI women 18.5 – 21.9 kg/sqm; optimal weight: BMI men 23.0 – 24.9 kg/sqm; BMI women 22.0 – 24.9 kg/sqm; overweight: BMI 25.0 – 29.9 kg/sqm; obesity: BMI ≥ 30 kg/sqm. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

	FEMALE	MALE	TOTAL
Underweight 2024	9,1	5,1	7,0
Normal weight 2024	43,4	43,2	43,3
Optimal weight 2024	29,2	22,5	25,7
Overweight 2024	13,7	24,0	19,2
Obesity 2024	4,6	5,2	4,9

Table 16: Weight categories of adults aged 18 and over (frequencies in %) 2024, underweight: BMI < 18.5 kg/sqm; normal weight: BMI men 18.5 – 22.9 kg/sqm; BMI women 18.5 – 21.9 kg/sqm; optimal weight: BMI men 23.0 – 24.9 kg/sqm; BMI women 22.0 – 24.9 kg/sqm; overweight: BMI 25.0 – 29.9 kg/sqm; obesity: BMI ≥ 30 kg/sqm. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

Nutritional Status

5b. Adults from 18 years

5b.iii Development of nutritional status 2000 – 2024

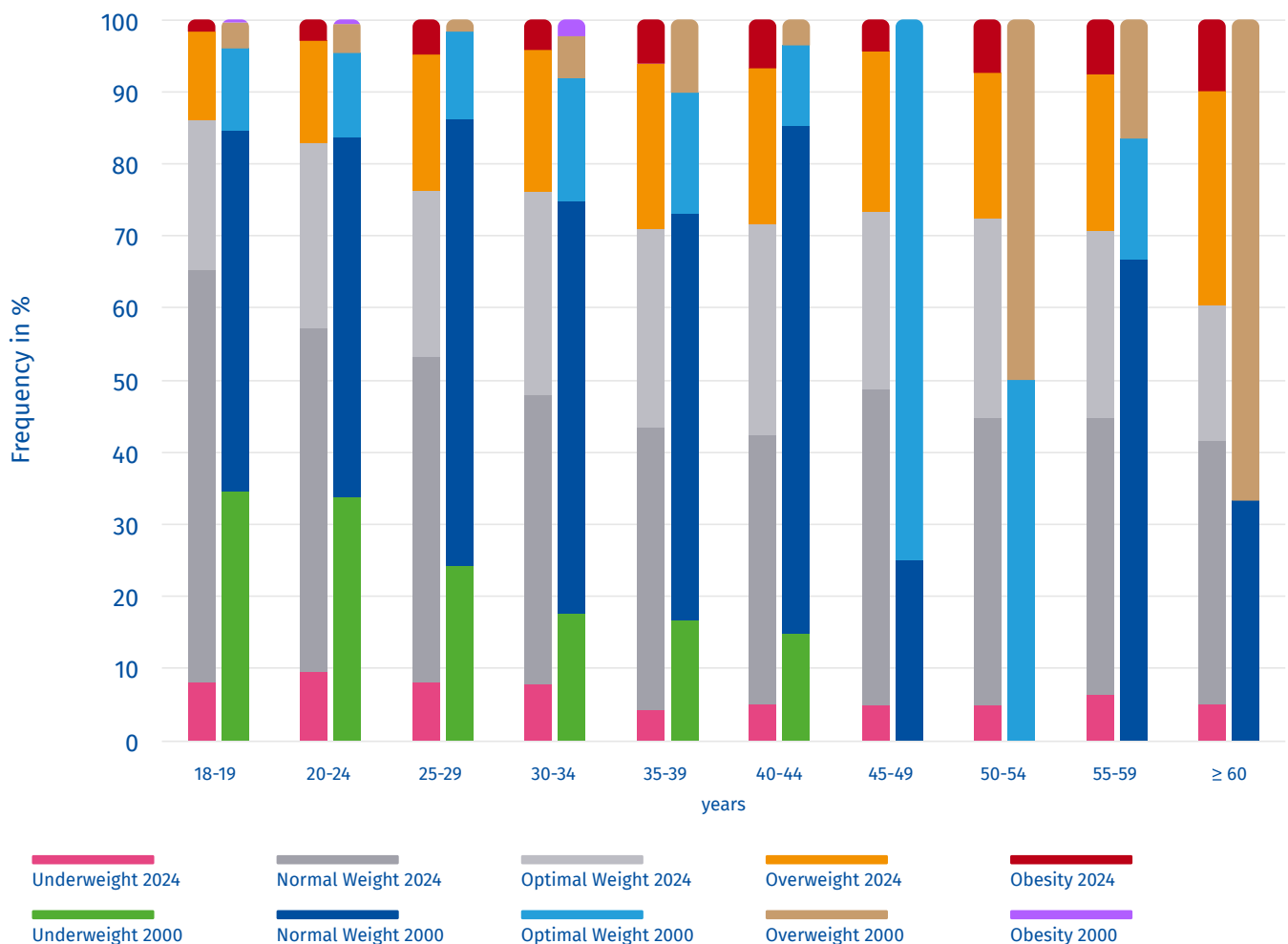


Fig. 17: Weight categories of adults aged 18 and over 2024, underweight: BMI < 18.5 kg/sqm; normal weight: BMI men 18.5 – 22.9 kg/sqm; BMI women 18.5 – 21.9 kg/sqm; optimal weight: BMI men 23.0 – 24.9 kg/sqm; BMI women 22.0 – 24.9 kg/sqm; overweight: BMI 25.0 – 29.9 kg/sqm; obesity: BMI ≥ 30 kg/sqm. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

Nutritional Status

5b. Adults from 18 years

5b.iii Development of nutritional status 2000 – 2024

YEAR	AGE IN YEARS									
	18 – 19	20 – 24	25 – 29	30 – 34	35 – 39	40 – 44	45 – 49	50 – 54	55 – 59	≥ 60
Underweight										
2000	34,5	33,6	24,2	17,5	16,7	14,8	0,0	0,0	0,0	0,0
2010	25,2	21,6	19,4	18,1	15,3	10,1	8,5	10,7	12,5	0,0
2020	18,2	13,7	10,3	8,8	7,8	8,9	6,5	7,4	7,7	8,7
2024	8,0	9,6	8,0	7,9	4,3	5,1	4,8	4,8	6,3	5,0
Normal weight										
2000	50,0	50,1	62,1	57,3	56,4	70,4	25,0	0,0	66,7	33,3
2010	54,1	56,4	57,2	54,2	55,9	60,8	50,0	50,0	50,0	54,5
2020	58,5	55,8	54,6	48,2	50,6	47,6	48,8	45,3	38,5	50,0
2024	57,2	47,6	45,2	39,9	39,1	37,3	44,0	39,9	38,5	36,6
Optimal weight										
2000	11,5	11,6	12,1	17,1	16,7	11,1	75,0	50,0	16,7	0,0
2010	15,4	14,7	14,3	20,1	17,3	16,9	23,2	25,0	12,5	9,1
2020	16,0	19,8	21,1	24,5	18,7	26,6	24,4	28,4	16,7	15,2
2024	20,9	25,6	23,1	28,3	27,5	29,2	24,4	27,7	25,9	18,8
Overweight										
2000	3,5	4,1	1,6	5,7	10,3	3,7	0,0	50,0	16,7	66,7
2010	5,3	6,8	7,8	6,0	10,9	8,5	13,4	10,7	12,5	27,3
2020	5,8	9,1	11,8	15,0	18,9	12,9	16,9	14,9	26,9	21,7
2024	12,2	14,2	18,8	19,6	23,0	21,7	22,4	20,2	21,7	29,7
Obesity										
2000	0,5	0,6	0,0	2,4	0,0	0,0	0,0	0,0	0,0	0,0
2010	0,0	0,6	1,3	1,7	0,5	3,7	4,9	3,6	12,5	9,1
2020	1,5	1,6	2,2	3,5	4,0	4,0	3,5	4,1	10,3	4,3
2024	1,6	2,9	4,9	4,3	6,1	6,7	4,4	7,4	7,7	9,9

Table 17: Development of weight categories of adults aged 18 and over (frequencies in %) 2000 – 2024, underweight: BMI < 18.5 kg/sqm; normal weight: BMI men 18.5 – 22.9 kg/sqm; BMI women 18.5 – 21.9 kg/sqm; optimal weight: BMI men 23.0 – 24.9 kg/sqm, BMI women 22.0 – 24.9 kg/sqm; overweight: BMI 25.0 – 29.9 kg/sqm; obesity: BMI ≥ 30 kg/sqm. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best lung function of the calendar year.

Nutritional Status

5b. Adults from 18 years

5b.iv Median BMI by birth cohort

Development of median BMI of adults aged 18 and over by birth cohorts 1991 – 2010 for data from years 2009 – 2024. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best FEV1% of the calendar year.

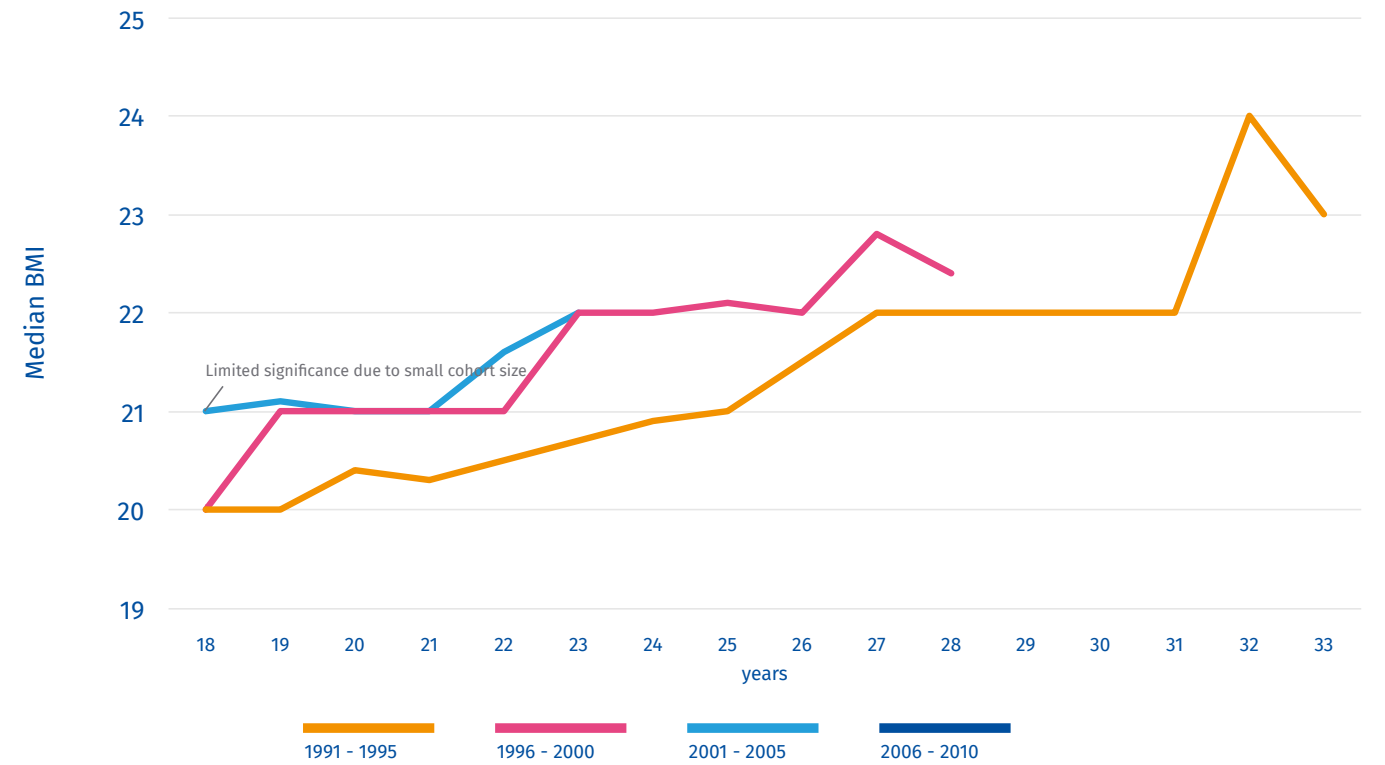


Fig. 18: Development of median BMI of adults aged 18 and over by birth cohorts 1991 – 2010 for data from years 2009 – 2024. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best FEV1% of the calendar year.

BIRTH COHORTS	AGE IN YEARS															
	18	19	21	21	22	23	24	25	26	27	28	29	30	31	32	33
1991 - 1995	20	20	20	20	21	21	21	21	22	22	22	22	22	22	24	23
1996 - 2000	20	21	21	21	21	22	22	22	22	23	22	-	-	-	-	-
2001 - 2005	21	21	21	21	22	22	-	-	-	-	-	-	-	-	-	-
2006 - 2010	21*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Table 18: Development of median BMI of adults aged 18 and over by birth cohorts 1991 – 2010 for data from years 2009 – 2024. Until 2014, the birthday-near BMI was recorded, from 2014 the BMI at the time of recording the best FEV1% of the calendar year.

* Limited significance due to small cohort size

Lung function

6a. Overview of lung function

For the lung function analysis, all patients from 6 years of age without transplantation, with lung function measurement 2024 were included. A total of 6063 datasets were available.

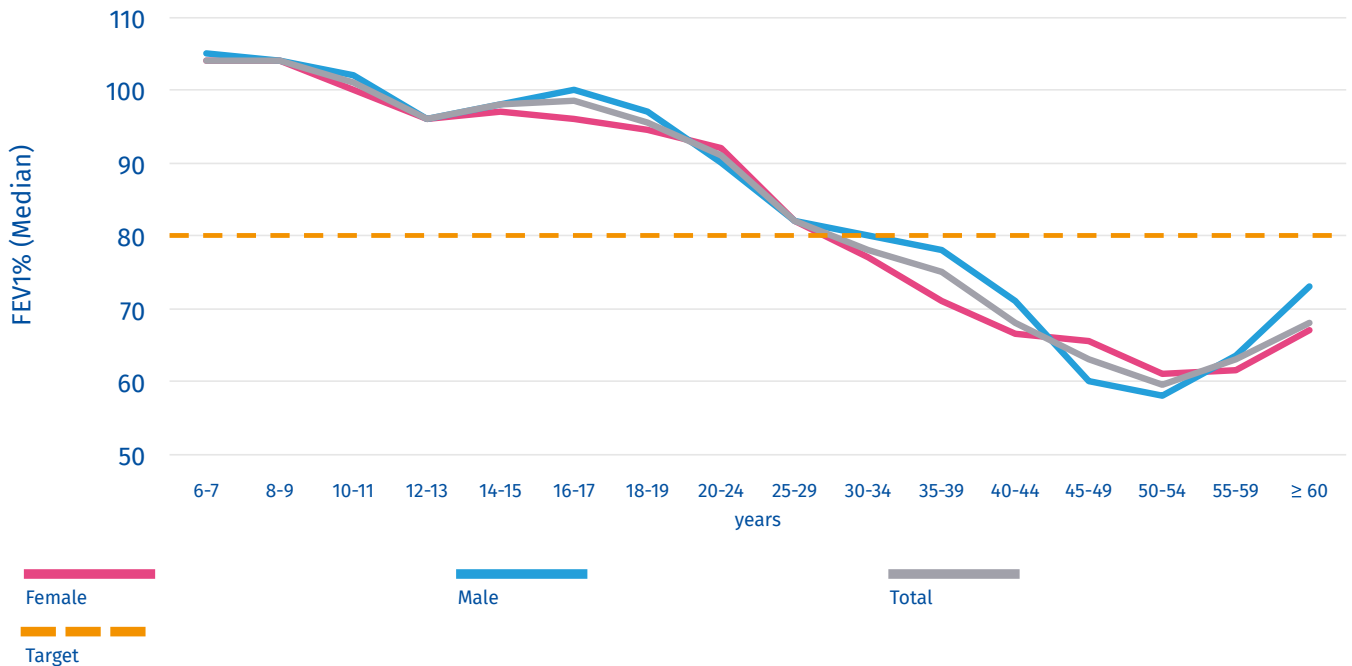


Fig. 19: FEV1% value 2024 according to Global Lung Function Initiative (GLI). Until 2014, the birthday-near FEV1% was recorded, from 2014 the best FEV1% of the calendar year.

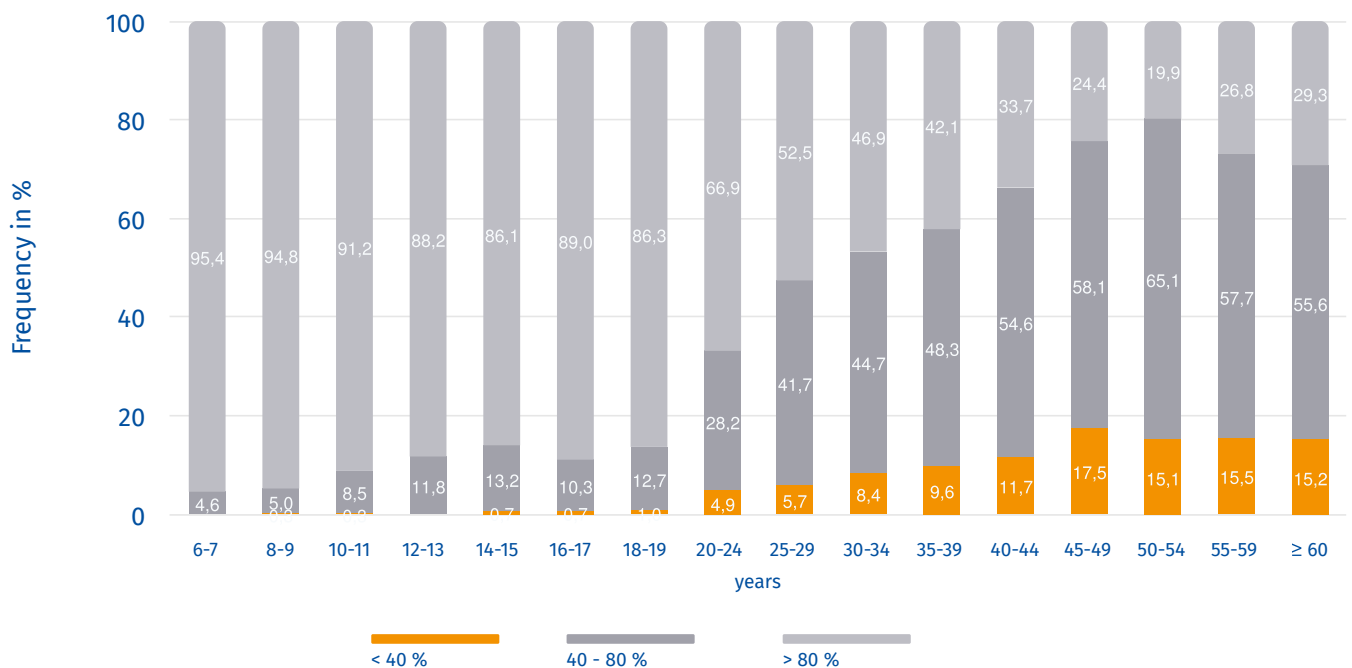


Fig. 20: Severity levels of FEV1% (categories < 40 %, 40 – 80 %, > 80 %) 2024 according to Global Lung Function Initiative (GLI). Until 2014, the birthday-near FEV1% was recorded, from 2014 the best FEV1% of the calendar year.

Lung function

6a. Overview of lung function

AGE	FEMALE			MALE			TOTAL		
	NUMBER	MEDIAN	25TH – 75TH PERCENTILE	NUMBER	MEDIAN	25TH – 75TH PERCENTILE	NUMBER	MEDIAN	25TH – 75TH PERCENTILE
6-7 years	184	104,0	97 - 111	186	105,0	96 - 113	370	104,0	96 - 113
8-9 years	164	104,0	96 - 111	179	104,0	95 - 112	343	104,0	96 - 112
10-11 years	148	100,0	89 - 108	169	102,0	93 - 109	317	101,0	91 - 109
12-13 years	175	96,0	88 - 106	155	96,0	89 - 105	330	96,0	88 - 105
14-15 years	143	97,0	87 - 107	159	98,0	88 - 106	302	98,0	88 - 107
16-17 years	176	96,0	87 - 106	124	100,0	90 - 108	300	99,0	89 - 107
18-19 years	162	95,0	85 - 104	152	97,0	88 - 108	314	96,0	86 - 107
20-24 years	364	92,0	70 - 103	350	90,0	77 - 101	714	91,0	73 - 102
25-29 years	349	82,0	63 - 96	399	82,0	62 - 97	748	82,0	62 - 96
30-34 years	319	77,0	59 - 95	346	80,0	58 - 95	665	78,0	58 - 95
35-39 years	250	71,0	52 - 89	325	78,0	57 - 94	575	75,0	55 - 92
40-44 years	180	67,0	53 - 81	232	71,0	49 - 92	412	68,0	50 - 89
45-49 years	110	66,0	49 - 80	136	60,0	43 - 80	246	63,0	45 - 80
50-54 years	83	61,0	47 - 74	103	58,0	43 - 84	186	60,0	44 - 76
55-59 years	70	62,0	47 - 80	72	64,0	45 - 86	142	63,0	46 - 85
≥ 60 years	49	67,0	48 - 82	50	73,0	49 - 86	99	68,0	48 - 84
< 18 years	990	100,0	90 - 109	972	101,0	91 - 109	1.962	100,0	91 - 109
≥ 18 years	1.936	78,0	59 - 96	2.165	81,0	58 - 96	4.101	80,0	59 - 96
Total	2.926	89,0	67 - 102	3.137	89,0	68 - 102	6.063	89,0	68 - 102

Table 19: FEV1% value 2024 according to Global Lung Function Initiative (GLI). Until 2014, the birthday-near FEV1% was recorded, from 2014 the best FEV1% of the calendar year.

Lung function

6b. Development of lung function 2000 – 2024

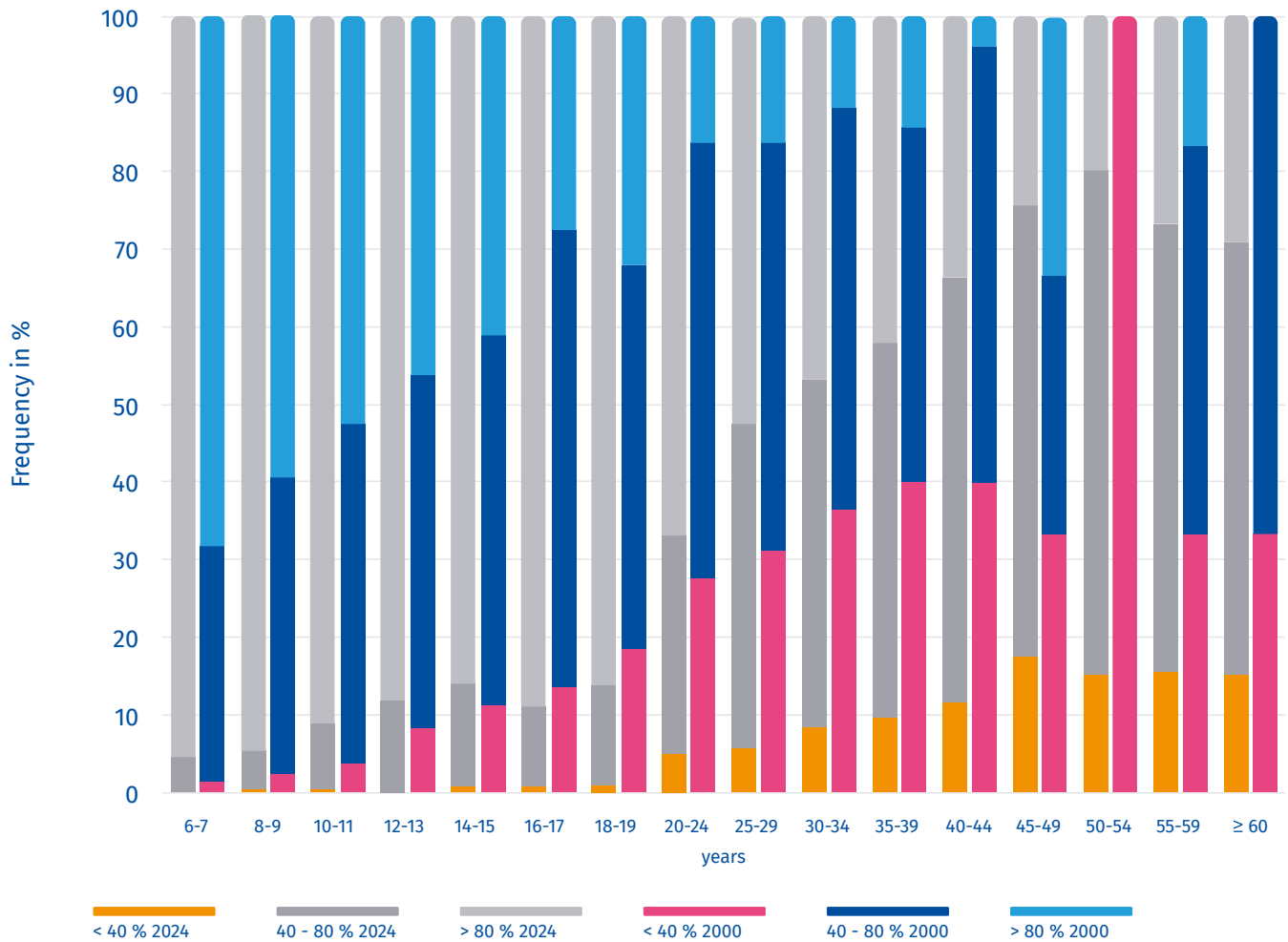


Fig. 21: Severity levels of FEV1% (categories < 40 %, 40 – 80 %, > 80 %) 2024 according to Global Lung Function Initiative (GLI). Until 2014, the birthday-near FEV1% was recorded, from 2014 the best FEV1% of the calendar year.

Lung function

6b. Development of lung function 2000 – 2024

YEAR	AGE IN YEARS															
	6–7	8–9	10–11	12–13	14–15	16–17	18–19	20–24	25–29	30–34	35–39	40–44	45–49	50–54	55–59	≥ 60
< 40 %																
2000	1,3	2,3	3,8	8,3	11,2	13,6	18,6	27,6	31,1	36,4	40,0	40,0	33,3	100,0	33,3	33,3
2010	0,9	3,0	2,7	4,9	3,9	9,9	15,4	19,5	28,2	32,6	36,7	37,4	32,1	44,4	33,3	40,0
2020	0,0	0,0	0,4	0,3	1,2	1,5	3,3	7,8	12,2	11,1	17,4	19,6	20,9	24,3	12,0	29,5
2024	0,0	0,3	0,3	0,0	0,7	0,7	1,0	4,9	5,7	8,4	9,6	11,7	17,5	15,1	15,5	15,2
40 - 80 %																
2000	30,4	38,3	43,6	45,4	47,6	58,8	49,4	56,1	52,5	51,8	45,7	56,0	33,3	0,0	50,0	66,7
2010	24,9	25,1	38,4	42,5	48,4	48,4	48,6	51,1	52,7	51,9	46,7	47,8	54,3	48,1	66,7	50,0
2020	10,2	12,9	14,9	21,9	21,5	30,5	37,2	49,3	51,0	55,6	55,0	58,3	63,8	53,4	69,3	50,0
2024	4,6	5,0	8,5	11,8	13,2	10,3	12,7	28,2	41,7	44,7	48,3	54,6	58,1	65,1	57,7	55,6
> 80 %																
2000	68,3	59,5	52,6	46,3	41,2	27,6	32,0	16,3	16,4	11,8	14,3	4,0	33,3	0,0	16,7	0,0
2010	74,2	71,9	58,9	52,6	47,7	41,7	36,0	29,4	19,0	15,5	16,6	14,8	13,6	7,4	0,0	10,0
2020	89,8	87,1	84,8	77,7	77,2	68,0	59,5	42,9	36,8	33,3	27,6	22,1	15,3	22,3	18,7	20,5
2024	95,4	94,8	91,2	88,2	86,1	89,0	86,3	66,9	52,5	46,9	42,1	33,7	24,4	19,9	26,8	29,3

Table 20: Development of age-related frequencies (in %) of the severity levels of FEV1% according to Global Lung Function Initiative (GLI) 2000 – 2024. Until 2014, the birthday-near FEV1% was recorded, from 2014 the best FEV1% of the calendar year.

Lung function

6c. Median FEV1% by birth cohort

Development of median FEV1% of children and adults by birth cohorts 1991 – 2020 for data from years 1997 – 2024. Until 2014, the birthday-near FEV1% was recorded, from 2014 the best FEV1% of the calendar year.

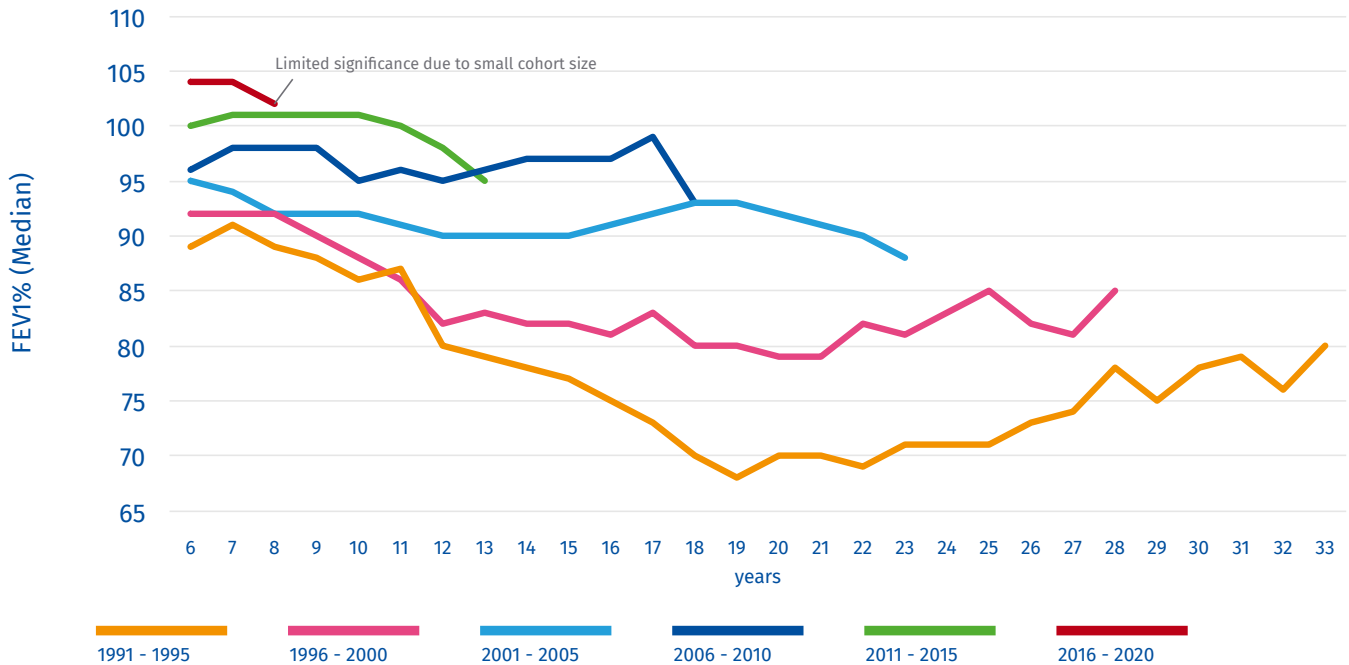


Fig. 22: Development of median FEV1% of children and adults by birth cohorts 1991 – 2020 for data from years 1997 – 2024. Until 2014, the birthday-near FEV1% was recorded, from 2014 the best FEV1% of the calendar year.

BIRTH-COHORTS	AGE IN YEARS																											
	6	7	8	9	10	11	12	13	14	15	16	17	18	19	21	21	22	23	24	25	26	27	28	29	30	31	32	33
1991 - 1995	89	91	89	88	86	87	80	79	78	77	75	73	70	68	70	70	69	71	71	71	73	74	78	75	78	79	76	80
1996 - 2000	92	92	92	90	88	86	82	83	82	82	81	83	80	80	79	79	82	81	83	85	82	81	85	-	-	-	-	-
2001 - 2005	95	94	92	92	92	91	90	90	90	90	91	92	93	93	92	91	90	88	-	-	-	-	-	-	-	-	-	-
2006 - 2010	96	98	98	98	95	96	95	96	97	97	97	99	93	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
2011 - 2015	100	101	101	101	101	100	98	95	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-
2016 - 2020	104	104	102*	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-	-

Table 21: Development of median FEV1% of children and adults by birth cohorts 1991 – 2020 for data from years 1997 – 2024. Until 2014, the birthday-near FEV1% was recorded, from 2014 the best FEV1% of the calendar year.

* Limited significance due to small cohort size

Lung infections

7a. At least once yearly detection

All patients without transplantation who had at least one microbiological examination in the calendar year 2024 (n=6.908) were included in the evaluation of lung infections. For 102 patients (1.5 %), there was no information on the microbiological examination in the calendar year.

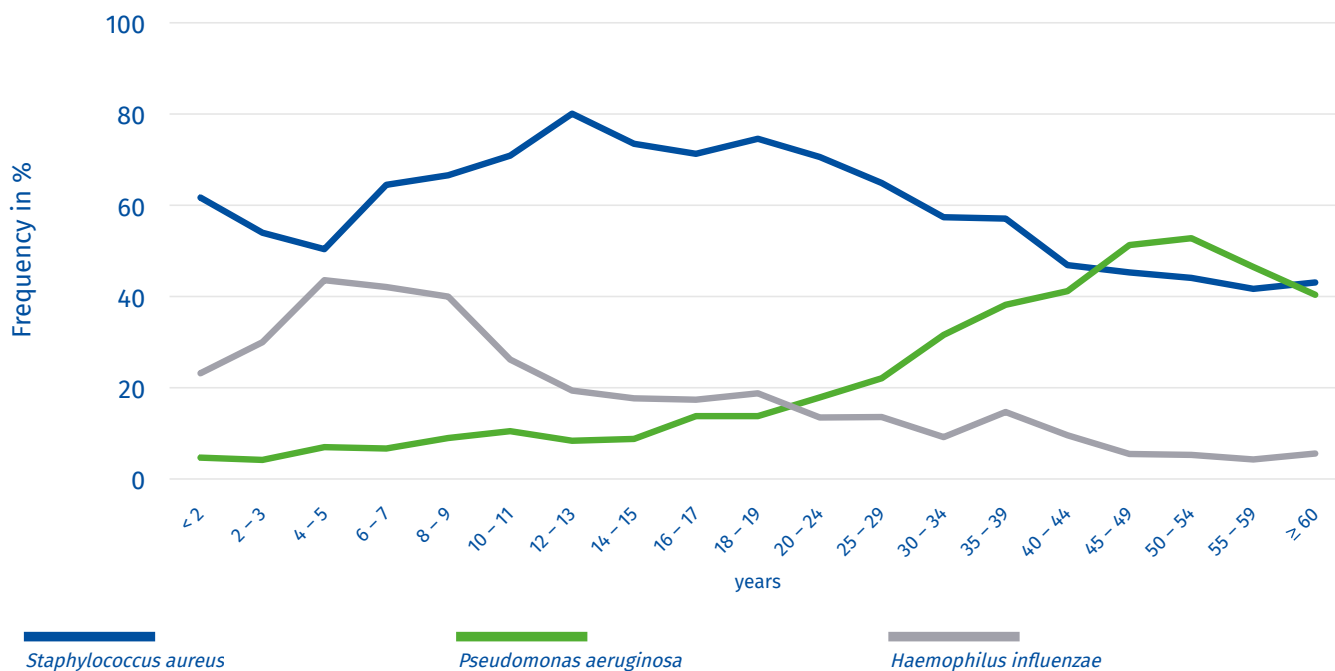


Fig. 23: Bacterial detections (*Staphylococcus aureus*, *Pseudomonas aeruginosa* and *Haemophilus influenzae*) in people with CF with microbiological examination 2024. There is no data for *Staphylococcus aureus* and *Haemophilus influenzae* before 2015.

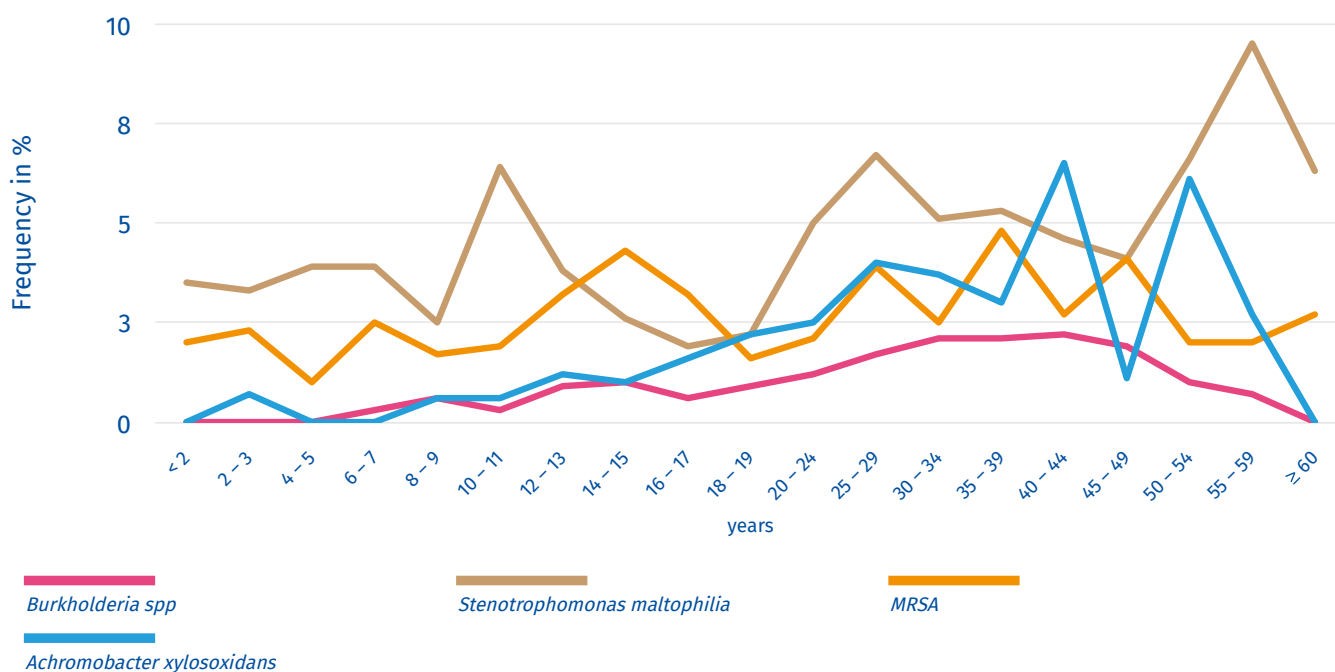


Fig. 24: Bacterial detections (*Burkholderia spp*, *Stenotrophomonas maltophilia*, *MRSA* and *Achromobacter xylosoxidans*) in people with CF with microbiological examination 2024. There is no data for these bacteria before 2015.

Lung infections

7a. At least once yearly detection

AGE	STAPHY- LOCOCCUS AUREUS INCL. MRSA	MRGN	PSEUDOMONAS AERUGINOSA	OF WHICH MRGN	BURKHOL- DERIA SPP	STENOTRO- PHOMONAS MALTOPHILIA	ACHROMO- BACTER XYLOSOXIDANS	HAEMOPHILUS INFLUENZAE
< 2 years	61,5	2,0	4,5	0,0	3,5	0,0	0,0	23,0
2 – 3 years	53,8	2,3	4,0	0,0	3,3	0,0	0,7	29,8
4 – 5 years	50,2	1,0	6,8	14,3	3,9	0,0	0,0	43,4
6 – 7 years	64,3	2,5	6,5	4,3	3,9	0,3	0,0	41,9
8 – 9 years	66,4	1,7	8,8	9,7	2,5	0,6	0,6	39,8
10 – 11 years	70,7	1,9	10,3	9,4	6,4	0,3	0,6	26,0
12 – 13 years	79,9	3,2	8,2	3,6	3,8	0,9	1,2	19,2
14 – 15 years	73,3	4,3	8,6	15,4	2,6	1,0	1,0	17,5
16 – 17 years	71,1	3,2	13,6	7,1	1,9	0,6	1,6	17,2
18 – 19 years	74,4	1,6	13,6	14,0	2,2	0,9	2,2	18,6
20 – 24 years	70,4	2,1	17,7	20,3	5,0	1,2	2,5	13,3
25 – 29 years	64,7	3,9	21,9	24,7	6,7	1,7	4,0	13,4
30 – 34 years	57,2	2,5	31,4	24,3	5,1	2,1	3,7	9,0
35 – 39 years	56,9	4,8	38,0	31,7	5,3	2,1	3,0	14,5
40 – 44 years	46,7	2,7	41,0	35,3	4,6	2,2	6,5	9,4
45 – 49 years	45,1	4,1	51,1	35,3	4,1	1,9	1,1	5,3
50 – 54 years	43,9	2,0	52,6	39,8	6,6	1,0	6,1	5,1
55 – 59 years	41,5	2,0	46,3	39,7	9,5	0,7	2,7	4,1
≥ 60 years	42,9	2,7	40,2	37,8	6,3	0,0	0,0	5,4
Total	61,6	2,8	21,8	26,8	4,6	1,2	2,3	18,5
< 18 years	66,5	2,5	8,5	8,8	3,5	0,5	0,7	28,7
≥ 18 years	58,1	3,1	31,5	30,3	5,4	1,6	3,5	11,0

Table 22: Bacterial detections in people with CF with microbiological examination (frequencies in %) 2024

Lung infections

7b. Development of infections with *Pseudomonas aeruginosa* 2000 – 2024

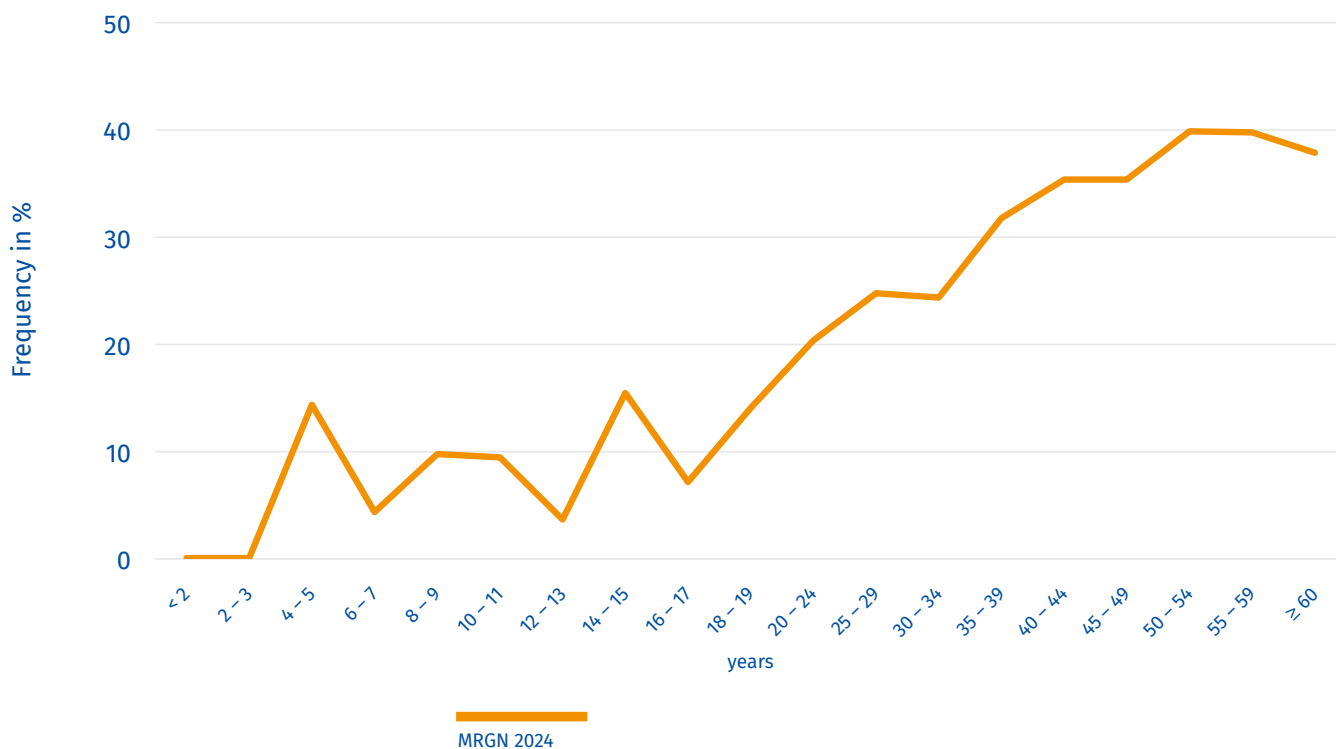


Fig. 25: Bacterial detections for PSA multiresistant (MRGN) in people with CF with PSA infection 2024. There is no data for PSA multiresistant before 2015.

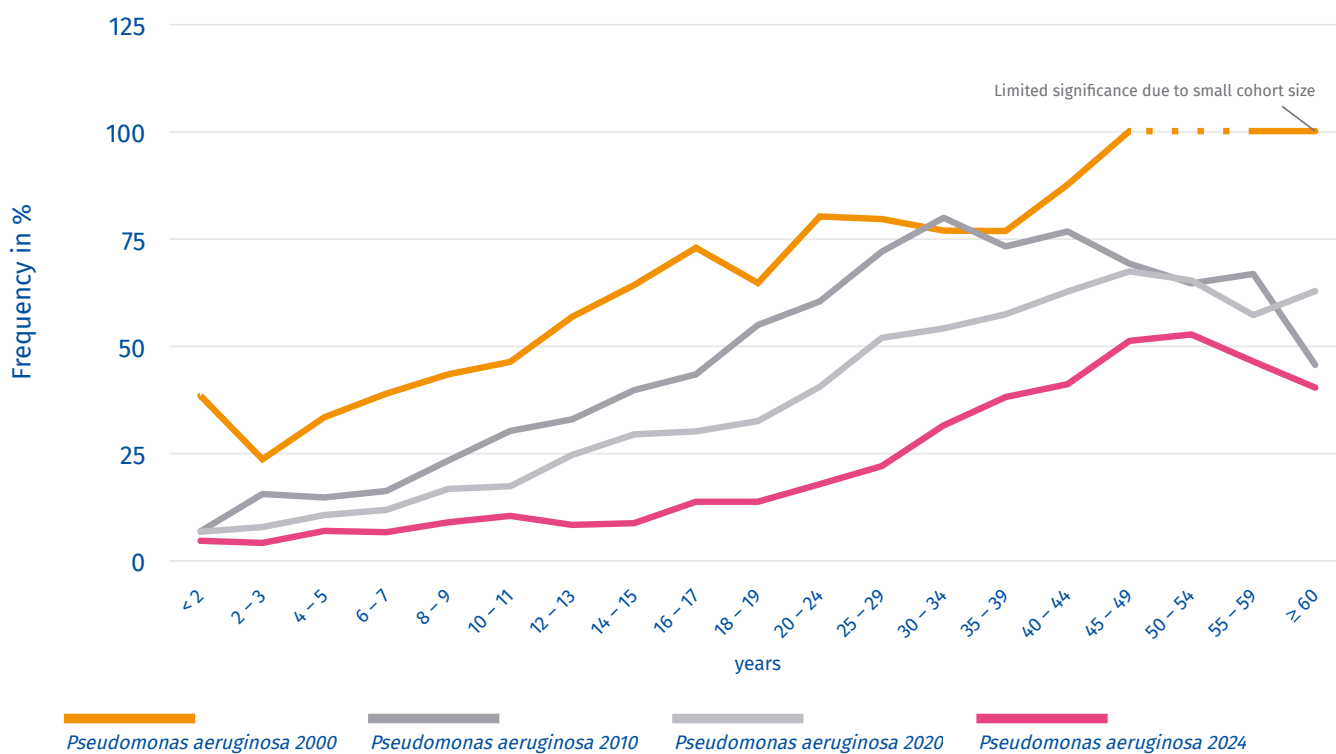


Fig. 26: *Pseudomonas aeruginosa* detections in people with CF with microbiological examination and at least once yearly detection 2024

Lung infections

7b. Development of infections with *Pseudomonas aeruginosa* 2000 – 2024

AGE	2000	2010	2020	2024
< 2 years	38,3	6,7	6,6	4,5
2 – 3 years	23,5	15,4	7,7	4,0
4 – 5 years	33,3	14,6	10,5	6,8
6 – 7 years	38,8	16,1	11,7	6,5
8 – 9 years	43,3	23,2	16,6	8,8
10 – 11 years	46,2	30,1	17,2	10,3
12 – 13 years	56,7	32,8	24,5	8,2
14 – 15 years	64,1	39,6	29,3	8,6
16 – 17 years	72,8	43,3	30,0	13,6
18 – 19 years	64,6	54,8	32,4	13,6
20 – 24 years	80,1	60,3	40,4	17,7
25 – 29 years	79,5	71,9	51,8	21,9
30 – 34 years	76,8	79,8	54,0	31,4
35 – 39 years	76,7	73,1	57,3	38,0
40 – 44 years	87,5	76,6	62,6	41,0
45 – 49 years	100,0	69,1	67,3	51,1
50 – 54 years	0,0	64,5	65,2	52,6
55 – 59 years	100,0	66,7	57,1	46,3
≥ 60 years	100,0	45,5	62,7	40,2
Total	57,1	46,9	36,6	21,8
< 18 years	48,3	28,2	18,1	8,5
≥ 18 years	77,1	68,9	52,2	31,5

Table 23: Development of *Pseudomonas aeruginosa* detections in people with CF with microbiological examination and at least once yearly detection (frequencies in %) 2000 – 2024

Lung infections

7c. Chronic lung infections

All patients without transplantation who had at least one microbiological examination in the calendar year 2024 (n=6.908) were included in the evaluation of chronic lung infections. For 102 patients (1.5 %), there was no information on the microbiological examination in the calendar year.

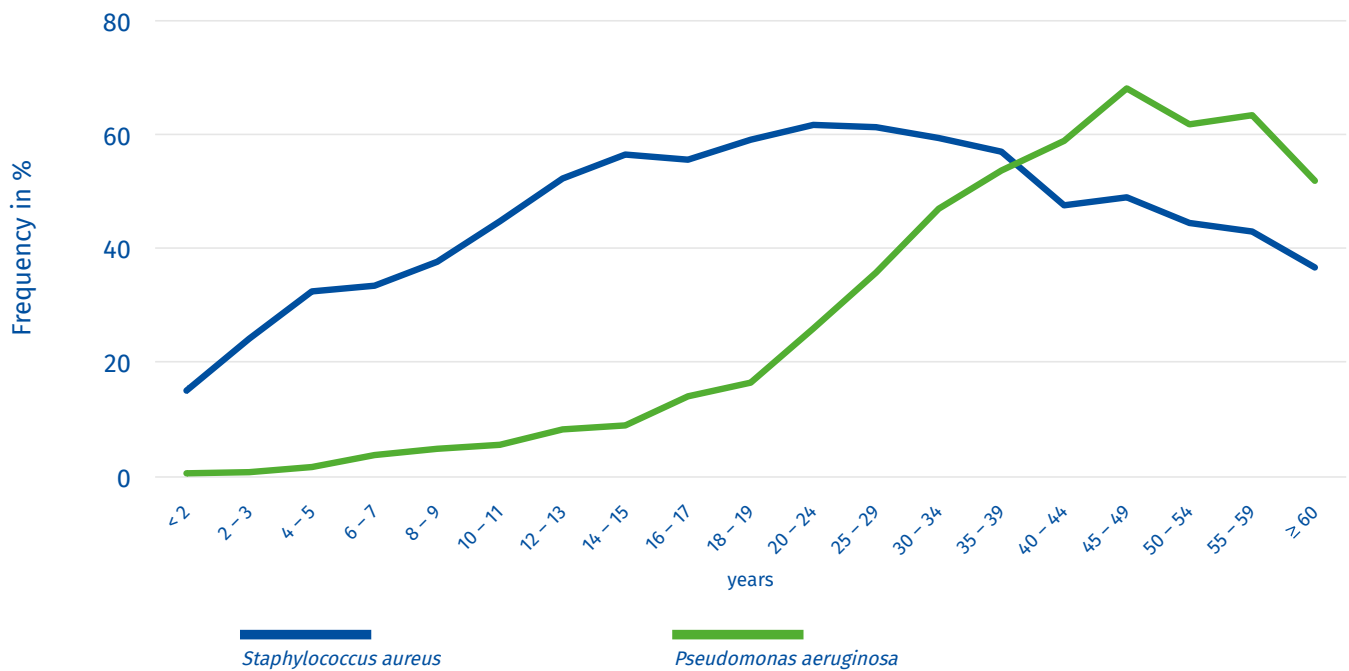


Fig. 27: Chronic lung infections in people with CF with microbiological examination 2024

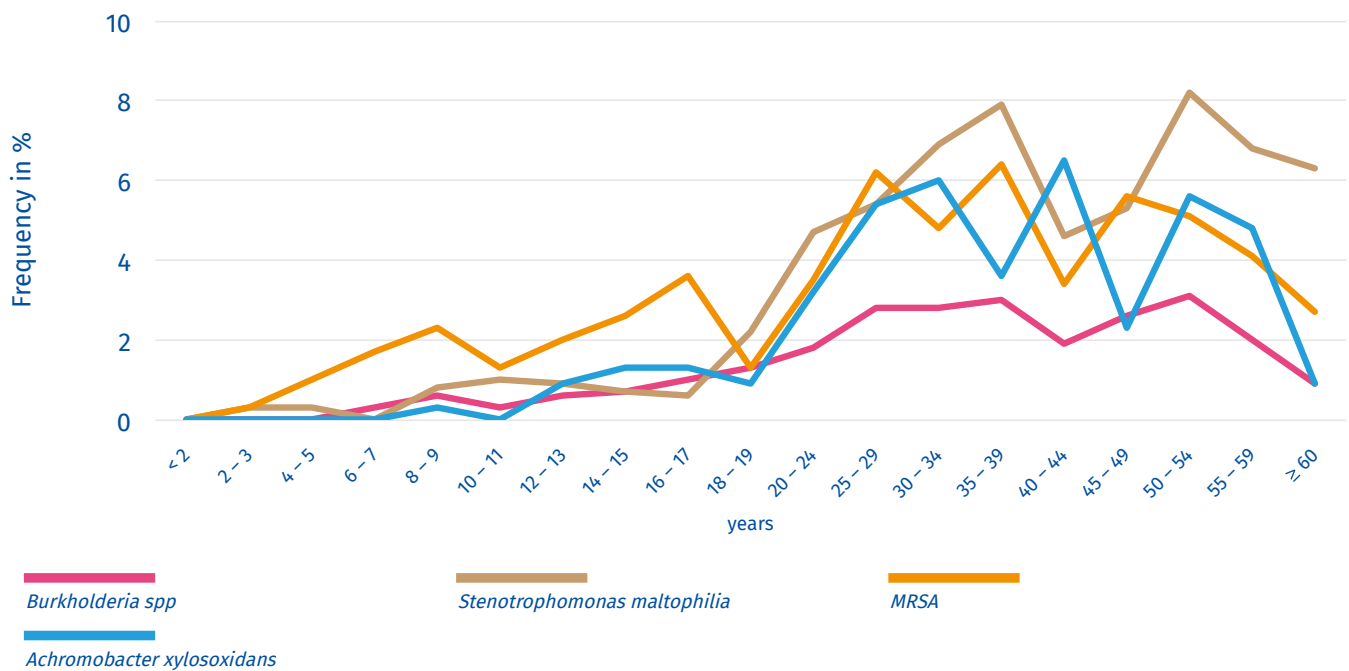


Fig. 28: Chronic lung infections in people with CF with microbiological examination (without representation of *Pseudomonas aeruginosa* and *Staphylococcus aureus*) 2024

Lung infections

7c. Chronic lung infections

AGE	CHRONIC					
	STAPHYLOCOCCUS AUREUS INCL. MRSA	MRSA	PSEUDOMONAS AERUGINOSA	BURKHOLDERIA SPP	STENOTRO- PHOMONAS MALTOPHILIA	ACHROMOBACTER XYLOSOXIDANS
< 2 years	15,0	0,0	0,5	0,0	0,0	0,0
2 – 3 years	24,1	0,3	0,7	0,3	0,0	0,0
4 – 5 years	32,4	1,0	1,6	0,3	0,0	0,0
6 – 7 years	33,4	1,7	3,7	0,0	0,3	0,0
8 – 9 years	37,6	2,3	4,8	0,8	0,6	0,3
10 – 11 years	44,7	1,3	5,5	1,0	0,3	0,0
12 – 13 years	52,2	2,0	8,2	0,9	0,6	0,9
14 – 15 years	56,4	2,6	8,9	0,7	0,7	1,3
16 – 17 years	55,5	3,6	14,0	0,6	1,0	1,3
18 – 19 years	59,0	1,3	16,4	2,2	1,3	0,9
20 – 24 years	61,6	3,5	25,9	4,7	1,8	3,2
25 – 29 years	61,2	6,2	35,7	5,4	2,8	5,4
30 – 34 years	59,3	4,8	46,9	6,9	2,8	6,0
35 – 39 years	56,9	6,4	53,6	7,9	3,0	3,6
40 – 44 years	47,5	3,4	58,8	4,6	1,9	6,5
45 – 49 years	48,9	5,6	68,0	5,3	2,6	2,3
50 – 54 years	44,4	5,1	61,7	8,2	3,1	5,6
55 – 59 years	42,9	4,1	63,3	6,8	2,0	4,8
≥ 60 years	36,6	2,7	51,8	6,3	0,9	0,9
Total	49,7	3,5	28,6	3,7	1,6	2,8
< 18 years	40,8	1,7	6,2	0,7	0,5	0,5
≥ 18 years	56,1	4,8	44,9	5,9	2,4	4,4

Table 24: Chronic lung infections in people with CF with microbiological examination (frequencies in %) 2024

Lung infections

7d. Atypical mycobacteria

All patients without transplantation and at least one examination for mycobacteria in the year 2024 (n=1.439) were included in the analysis.

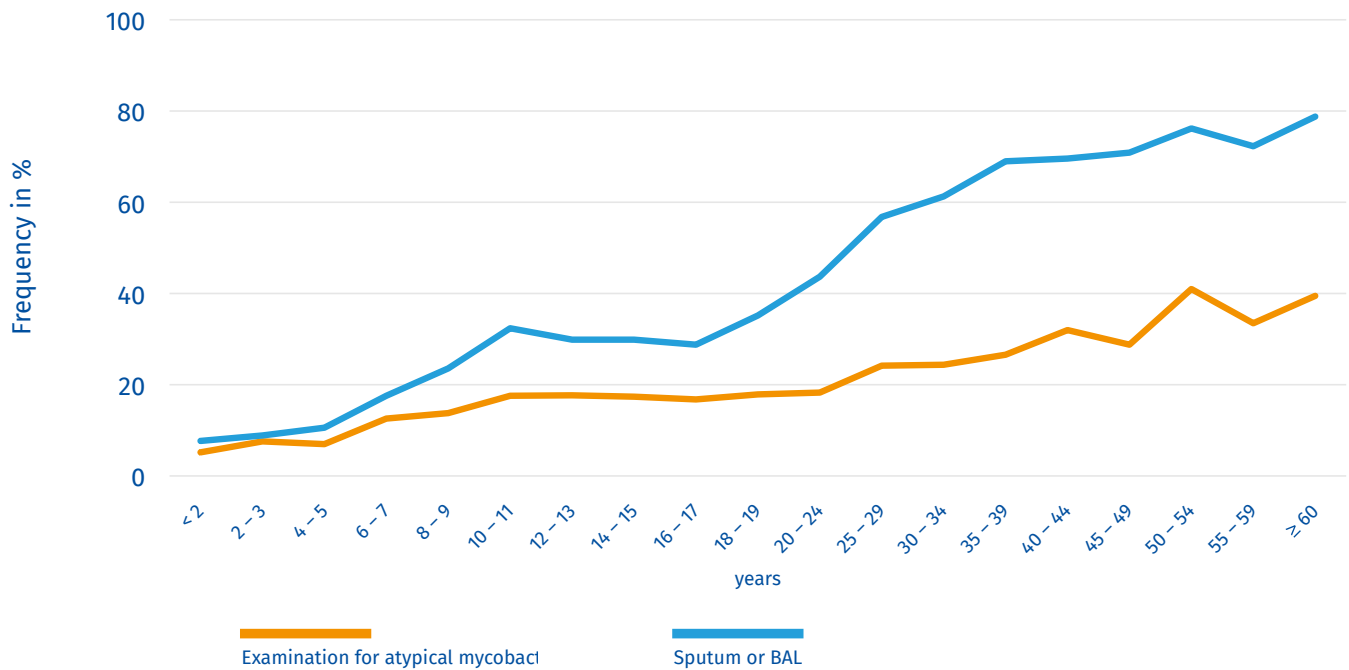


Fig. 29: Frequencies of patients with sputum or BAL and the examinations for atypical mycobacteria performed 2024

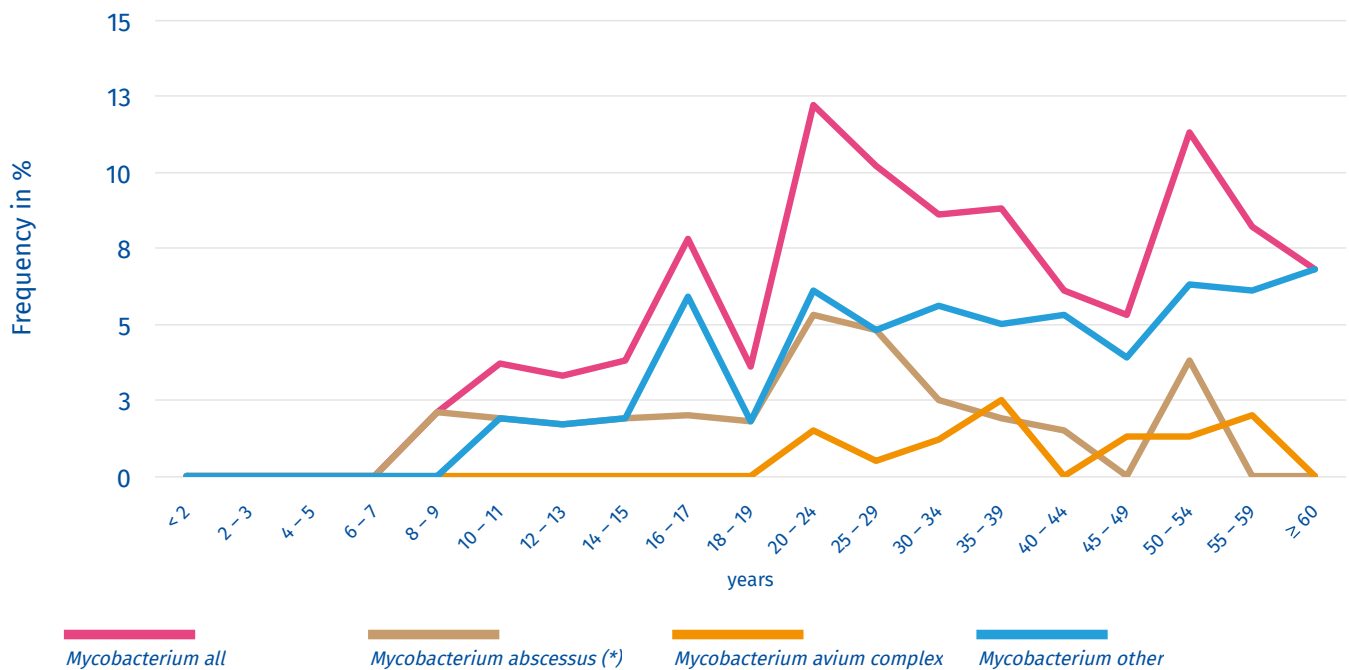


Fig. 30: Age-dependent frequency of patients with examinations for atypical mycobacteria 2024

(*) *Mycobacterium abscessus* includes *Mycobacterium abscessus bolleti*, *Mycobacterium abscessus massiliense*, *Mycobacterium abscessus abscessus* and *Mycobacterium abscessus*, multiple mentions possible.

Lung infections

7d. Atypical mycobacteria

AGE	SPUTUM OR BAL - NUMBER ¹	SPUTUM OR BAL - FREQUENCY IN % ¹	EXAM. FOR ATYPICAL MYCOBACT. - NUMBER ²	EXAM. FOR ATYPICAL MYCOBACT. - FREQUENCY IN % ²	<i>Mycobacterium</i> <i>abscessus</i> - NUMBER ^{3 4}	<i>Mycobacterium</i> <i>abscessus</i> - FREQUENCY IN % ^{3 4}	<i>Mycobacterium avium</i> <i>complex</i> - NUMBER ³	<i>Mycobacterium avium</i> <i>complex</i> - FREQUENCY IN % ³	<i>Mycobacterium other</i> - NUMBER ³	<i>Mycobacterium other</i> - FREQUENCY IN % ³	<i>Mycobacterium all</i> - NUMBER ³	<i>Mycobacterium all</i> - FREQUENCY IN % ³
< 2 years	15	7,5	10	66,7	0	0,0	0	0,0	0	0,0	0	0,0
2 – 3 years	26	8,7	22	84,6	0	0,0	0	0,0	0	0,0	0	0,0
4 – 5 years	32	10,4	21	65,6	0	0,0	0	0,0	0	0,0	0	0,0
6 – 7 years	62	17,4	44	71,0	0	0,0	0	0,0	0	0,0	0	0,0
8 – 9 years	83	23,4	48	57,8	1	2,1	0	0,0	0	0,0	1	2,1
10 – 11 years	100	32,2	54	54,0	1	1,9	0	0,0	1	1,9	2	3,7
12 – 13 years	102	29,7	60	58,8	1	1,7	0	0,0	1	1,7	2	3,3
14 – 15 years	90	29,7	52	57,8	1	1,9	0	0,0	1	1,9	2	3,8
16 – 17 years	88	28,6	51	58,0	1	2,0	0	0,0	3	5,9	4	7,8
18 – 19 years	111	35,0	56	50,5	1	1,8	0	0,0	1	1,8	2	3,6
20 – 24 years	314	43,5	131	41,7	7	5,3	2	1,5	8	6,1	16	12,2
25 – 29 years	440	56,6	187	42,5	9	4,8	1	0,5	9	4,8	19	10,2
30 – 34 years	409	61,1	162	39,6	4	2,5	2	1,2	9	5,6	14	8,6
35 – 39 years	416	68,8	160	38,5	3	1,9	4	2,5	8	5,0	14	8,8
40 – 44 years	288	69,4	132	45,8	2	1,5	0	0,0	7	5,3	8	6,1
45 – 49 years	188	70,7	76	40,4	0	0,0	1	1,3	3	3,9	4	5,3
50 – 54 years	149	76,0	80	53,7	3	3,8	1	1,3	5	6,3	9	11,3
55 – 59 years	106	72,1	49	46,2	0	0,0	1	2,0	3	6,1	4	8,2
≥ 60 years	88	78,6	44	50,0	0	0,0	0	0,0	3	6,8	3	6,8
Total	3.107	44,3	1.439	20,5	34	2,4	12	0,8	62	4,3	104	7,2
< 18 years	656	22,2	394	60,1	5	1,3	0	0,0	6	1,5	11	2,8
≥ 18 years	2.451	60,4	1.045	42,6	29	2,8	12	1,1	56	5,4	93	8,9

Table 25: People with CF with an examination for atypical mycobacteria (frequency in %) 2024

¹ Sputum or BAL: Based on all patients with microbiological examination

² Examination for atypical mycobacteria: Based on patients with sputum/BAL

³ For individual mycobacteria: Based on patients with examination for atypical mycobacteria performed

⁴ *Mycobacterium abscessus* includes *Mycobacterium abscessus bolleti*, *Mycobacterium abscessus massiliense*, *Mycobacterium abscessus abscessus* and *Mycobacterium abscessus*, multiple mentions possible.

Complications extended

8a. Overview

COMPLICATIONS	AGE IN YEARS									
	0 - 5	6 - 11	12 - 17	18 - 29	30 - 39	40 - 49	50 - 59	≥ 60	< 18	≥ 18
Allergic bronchopulmonary aspergillosis (ABPA)	0,1	0,3	1,8	3,0	3,2	2,2	2,3	4,5	0,8	2,9
Hemoptysis	0,0	0,0	0,4	1,8	3,7	3,8	4,1	3,6	0,1	2,9
of which at least one massive episode (> 240 ml in 24h)	0,0	0,0	0,0	0,0	0,0	0,0	0,0	0,0	0,0	0,0
Pneumothorax	0,1	0,0	0,1	0,2	0,1	0,3	0,3	0,9	0,1	0,2
of which requiring drainage	0,0	0,0	100,0	33,3	100,0	100,0	100,0	0,0	50,0	62,5
Respiratory failure	0,9	0,6	0,6	3,7	6,9	9,6	16,3	15,2	0,7	6,9
of which partial respiratory failure	71,4	83,3	66,7	67,2	60,2	70,8	71,4	52,9	73,7	65,9
of which total respiratory failure	28,6	16,7	16,7	19,4	17,0	15,4	14,3	23,5	21,1	17,1
Exocrine pancreatic insufficiency	86,7	88,6	89,5	88,7	85,2	83,8	80,8	67,0	88,4	85,7
Distal intestinal obstruction syndrome (DIOS)	1,9	1,9	2,4	2,7	2,7	2,5	2,0	0,0	2,0	2,5
Liver disease	8,3	22,4	33,8	45,0	40,7	40,4	40,1	37,5	22,2	42,4
of which liver cirrhosis	0,0	5,7	14,9	17,8	15,9	13,5	13,0	9,5	9,9	16,0
of which cirrhosis with portal hypertension	0,0	1,7	6,8	8,1	6,7	7,3	7,2	4,8	4,2	7,4
of which cirrhosis without portal hypertension	0,0	3,9	7,1	6,5	5,6	4,0	2,2	0,0	5,2	5,3
Gastroesophageal reflux	1,2	1,0	3,2	5,8	6,3	8,5	11,9	17,0	1,8	7,2
Diabetes mellitus	0,2	1,3	8,9	22,8	31,0	41,6	47,7	36,6	3,6	30,7
of which type 3	0,0	53,8	91,8	96,1	95,2	98,9	95,1	95,1	85,0	96,3
of which non-type 3	100,0	46,2	8,2	3,9	4,8	1,1	4,9	4,9	15,0	3,7
Osteopenia	0,0	0,3	0,8	10,4	18,6	25,9	29,4	30,4	0,4	17,5
Osteoporosis	0,0	0,0	0,1	4,1	8,6	14,0	23,0	29,5	0,0	9,2
Arthritis / Arthropathy	0,0	0,2	0,7	3,1	5,7	9,1	12,2	11,6	0,3	5,8
Pansinusitis / Polyps	2,6	10,5	17,8	27,6	33,5	35,7	31,1	38,4	10,7	31,2
Hearing loss	0,4	0,6	1,4	1,4	2,3	3,5	7,0	10,7	0,8	2,7
Renal failure	0,1	0,2	0,0	0,6	1,6	4,1	5,2	4,5	0,1	2,0
Depression	0,0	0,0	1,5	8,3	7,5	8,4	5,2	7,1	0,5	7,8
Malignant disease	0,1	0,0	0,1	0,3	0,6	2,5	6,7	13,4	0,1	1,6
Salt wasting syndrome	1,1	0,6	0,1	0,1	0,2	0,0	0,0	0,0	0,6	0,1

Table 26: People with CF with complications (frequencies in %) 2024

Complications extended

8b. Diabetes mellitus and liver disease

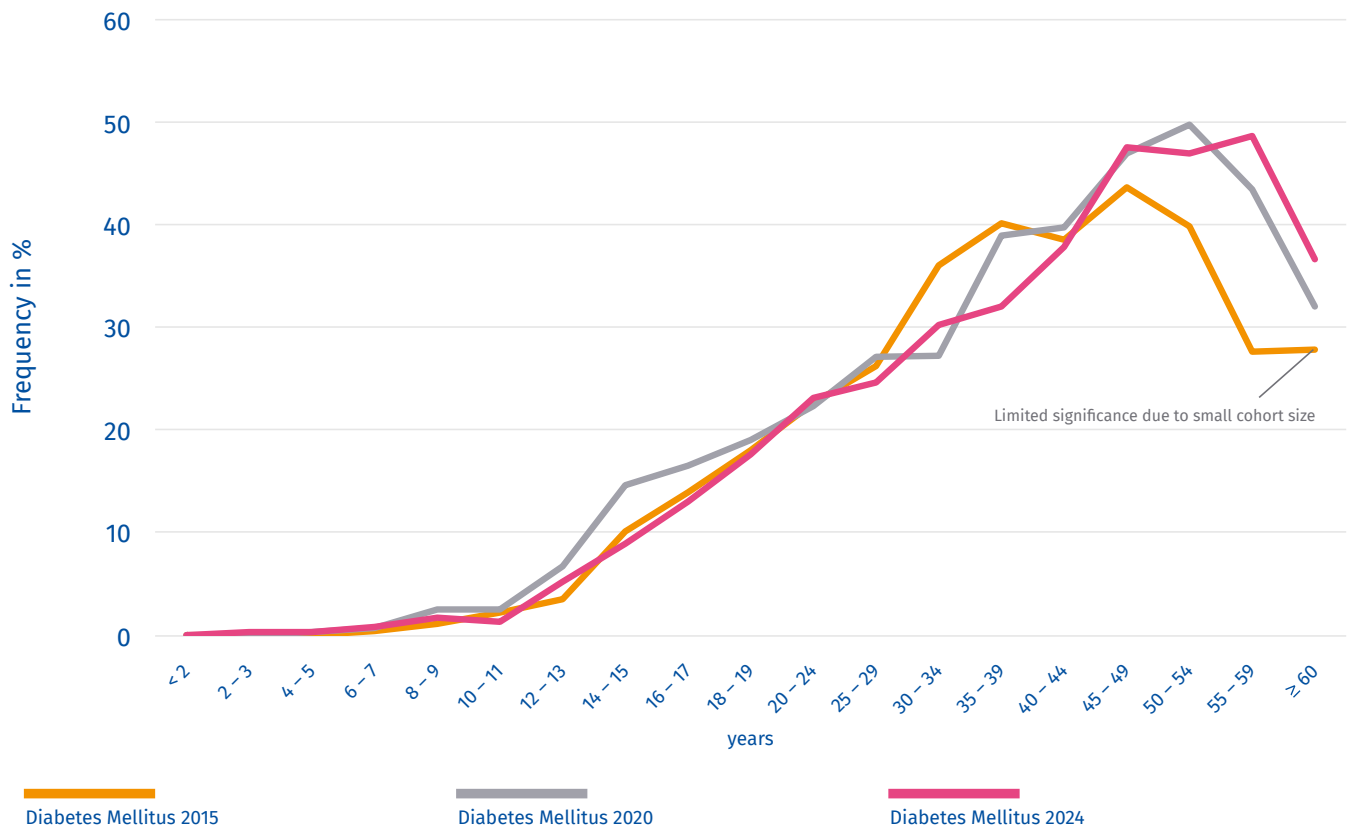


Fig. 31: Development of diabetes detection in people with CF 2024

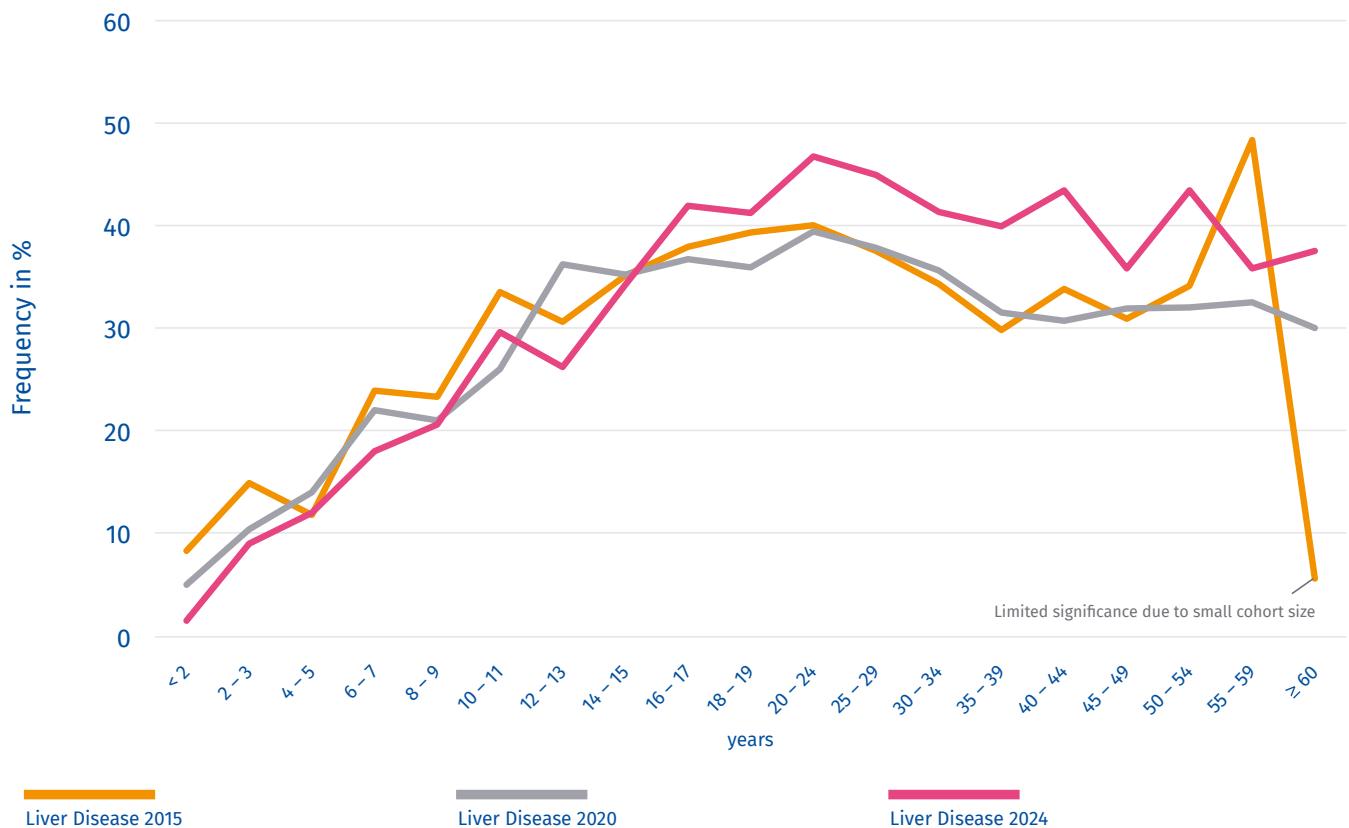


Fig. 32: Development of liver diseases in people with CF 2024

Complications extended

8c. Number of antibiotic-treated exacerbations

Number of antibiotic-treated exacerbations per Cystic Fibrosis patient (frequencies in %) 2024

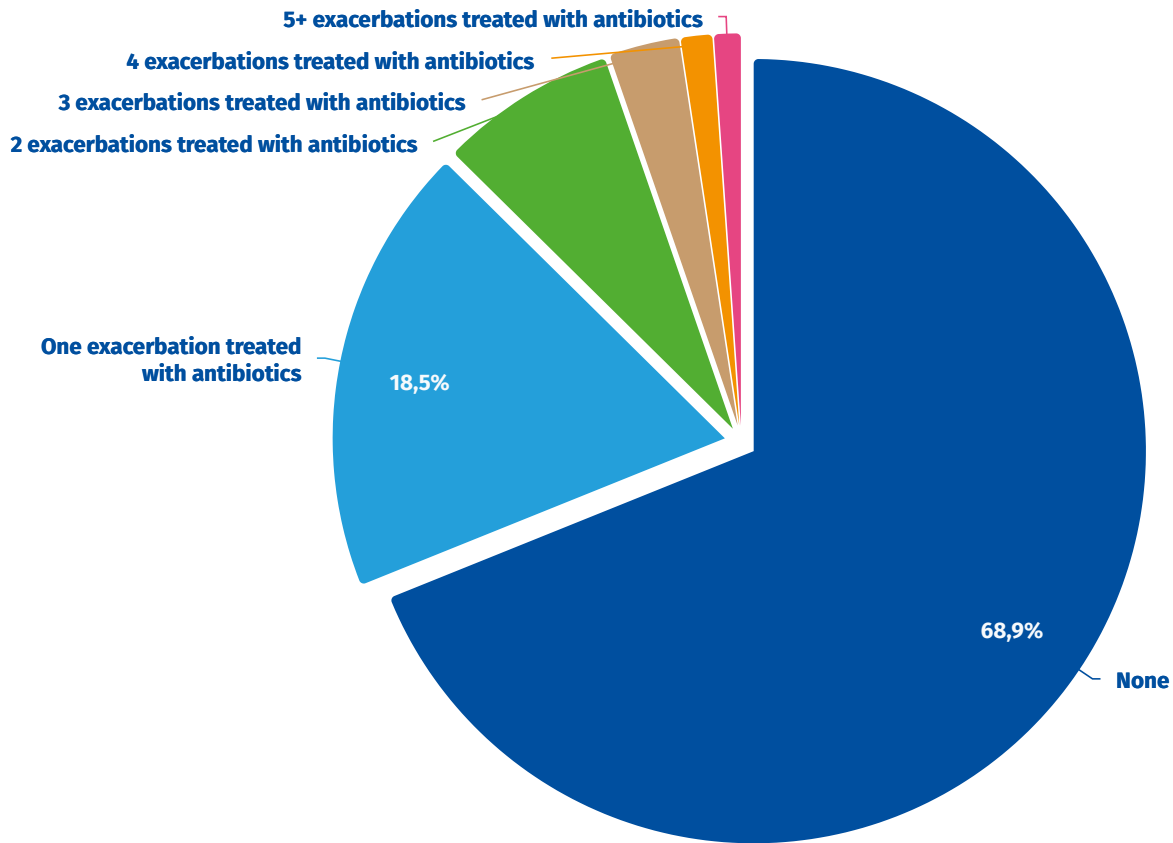


Fig. 33: Number of antibiotic-treated exacerbations per Cystic Fibrosis patient (frequencies in %) 2024

NUMBER PER PATIENT	0 – 5	6 – 11	12 – 17	18 – 29	30 – 39	≥ 40	TOTAL	< 18	≥ 18
0	61,6	67,9	73,0	72,5	69,5	65,4	68,9	67,8	69,6
1	20,5	18,1	15,7	17,1	18,5	21,7	18,5	18,0	18,8
2	9,0	8,8	6,6	5,7	7,2	7,9	7,3	8,1	6,8
3	4,2	3,3	3,3	2,5	2,2	3,0	2,9	3,6	2,5
4	2,1	0,8	0,7	1,3	1,5	1,4	1,3	1,1	1,4
5+	2,6	1,1	0,6	0,9	1,1	0,6	1,1	1,4	0,9
unknown	0,0	0,0	0,0	0,0	0,0	0,0	0,0	0,0	0,0

Table 27: Number of antibiotic-treated exacerbations per Cystic Fibrosis patient (frequencies in %) 2024

Complications extended

8d. Antibiotic-treated exacerbations

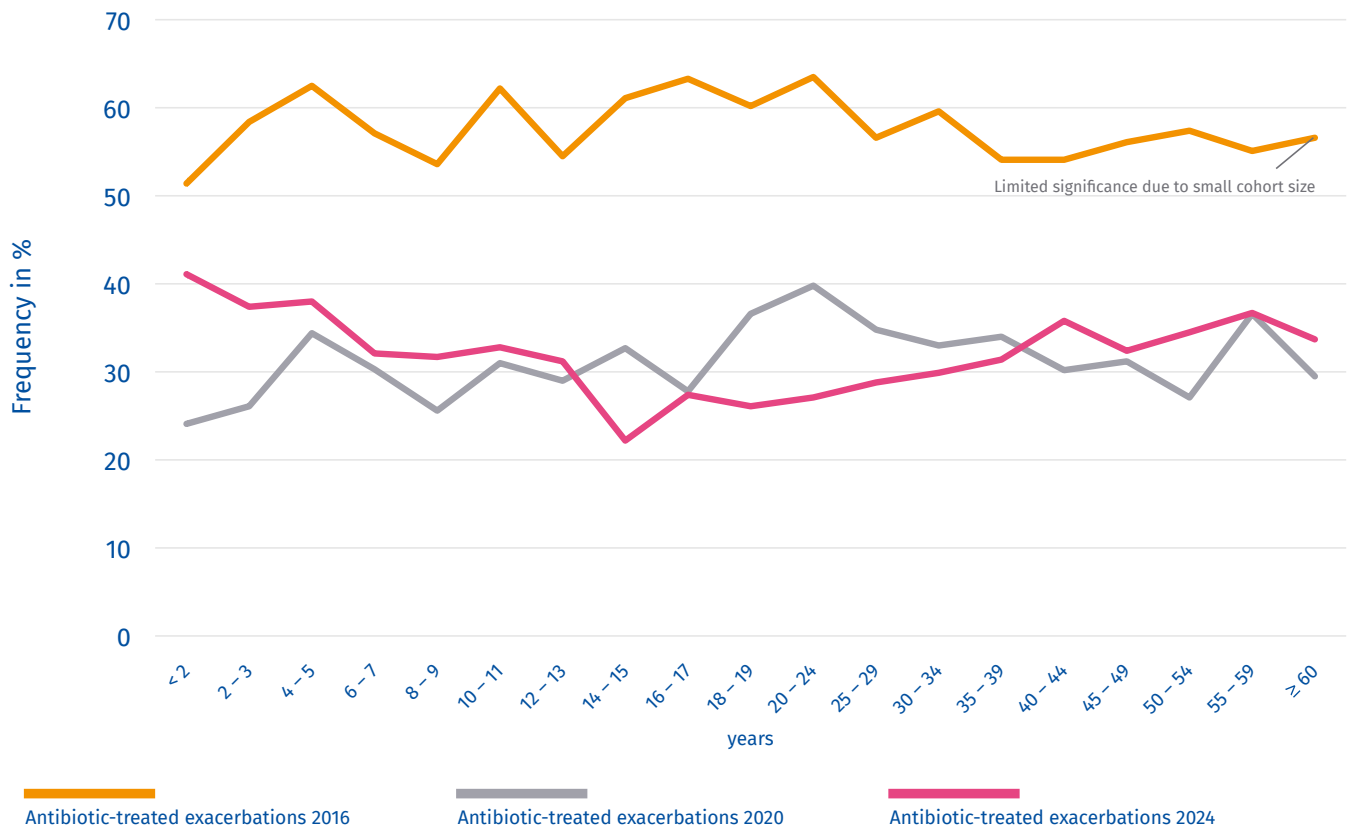


Fig. 34: Development of age-related frequencies of people with CF with at least 1 antibiotic-treated exacerbation 2016 - 2024

YEAR	< 2	2 - 3	4 - 5	6 - 7	8 - 9	10 - 11	12 - 13	14 - 15	16 - 17	18 - 19	20 - 24	25 - 29	30 - 34	35 - 39	40 - 44	45 - 49	50 - 54	55 - 59	≥ 60
2024	41,0	37,3	37,9	32,0	31,6	32,7	31,1	22,1	27,3	26,0	27,0	28,7	29,8	31,3	35,7	32,3	34,4	36,6	33,6
2023	29,4	34,6	38,3	33,2	24,9	24,2	23,9	20,6	24,5	23,2	29,5	24,3	27,4	32,3	34,2	30,2	30,4	32,3	28,3
2022	31,3	37,8	43,3	33,8	28,6	29,9	25,5	23,0	20,8	20,1	28,5	29,4	26,0	30,9	30,1	28,8	31,2	19,1	32,1
2021	29,7	35,0	36,0	26,9	28,7	26,6	20,5	17,7	16,3	20,7	24,1	24,5	19,7	25,2	23,6	24,3	18,0	19,1	30,5
2020	24,0	26,0	34,3	30,2	25,5	30,9	28,9	32,6	27,7	36,5	39,7	34,7	32,9	33,9	30,1	31,1	27,0	36,5	29,4
2019	35,8	35,7	41,2	39,7	38,9	36,3	41,9	37,9	47,4	48,3	50,7	43,7	51,2	46,0	41,4	46,5	45,1	48,1	61,9
2018	27,7	37,7	40,7	38,7	40,0	39,7	35,4	34,1	45,8	44,2	48,8	47,3	47,0	48,2	48,5	44,2	48,0	52,3	57,6
2017	46,4	59,5	58,9	60,5	60,2	58,1	62,1	66,4	64,0	59,8	56,2	58,0	59,4	56,4	58,6	57,0	52,9	59,3	53,6
2016	51,3	58,3	62,4	57,0	53,5	62,1	54,4	61,0	63,2	60,1	63,4	56,5	59,5	54,0	54,0	56,0	57,3	55,0	56,5

Table 28: Development of age-related frequencies (in %) of people with CF with at least 1 antibiotic-treated exacerbation over the years

Therapies

9a. Children and adolescents under 18 years

9a.i Basic therapy

All patients without transplantation who answered the question about gastrointestinal or pulmonary long-term therapy were included in the evaluation of basic therapy. Datasets from 2.783 patients under 18 years were included in the analyses. For 0 patients (0.0 %), the question about gastrointestinal or pulmonary long-term therapy was not answered.

BASIC THERAPY	AGE IN YEARS			
	0 - 5	6 - 11	12 - 17	TOTAL
DNase	12,6	32,9	44,4	31,0
Mannitol	0,0	0,0	0,2	0,1
Hypertonic saline solution (≥ 3 %)	91,6	96,8	91,7	93,5
of which 3 – 5.7 %	21,9	17,2	14,6	17,7
of which ≥ 5.8 %	78,1	82,8	85,4	82,3
At least one mucolytic therapy (mannitol, DNase, hypertonic saline solution ≥ 3 %)	91,8	97,3	93,8	94,5
Short-acting β 2-sympathomimetics (SABA)	59,1	66,5	64,2	63,6
Long-acting β 2-sympathomimetics (LABA)	5,0	10,6	17,7	11,4
Anticholinergics	3,8	7,2	11,5	7,7
Anti-staphylococcal therapy	7,3	5,2	7,1	6,5
Nasal steroids	9,7	19,5	20,9	17,1
Inhaled steroids	7,4	13,7	18,8	13,7
Oral steroids	0,2	0,5	1,4	0,7
Vitamin A	79,4	81,0	79,3	79,9
Vitamin D	96,9	96,0	95,8	96,2
Vitamin E	67,3	66,9	73,1	69,1
Vitamin K	75,6	76,3	73,2	75,0
Hormonal contraception in women (collected from age 14)	-	-	7,4	7,4

Table 29: People with CF under 18 years with basic therapy (frequencies in %) 2024

Therapies

9a. Children and adolescents under 18 years

9a.ii Inhalation and combination therapies

In the graph for inhalation and combination therapies, all minors who answered the question about pulmonary long-term therapy were included (2.783 patients). 141 patients (5.1 %) of these received no inhalation therapy.

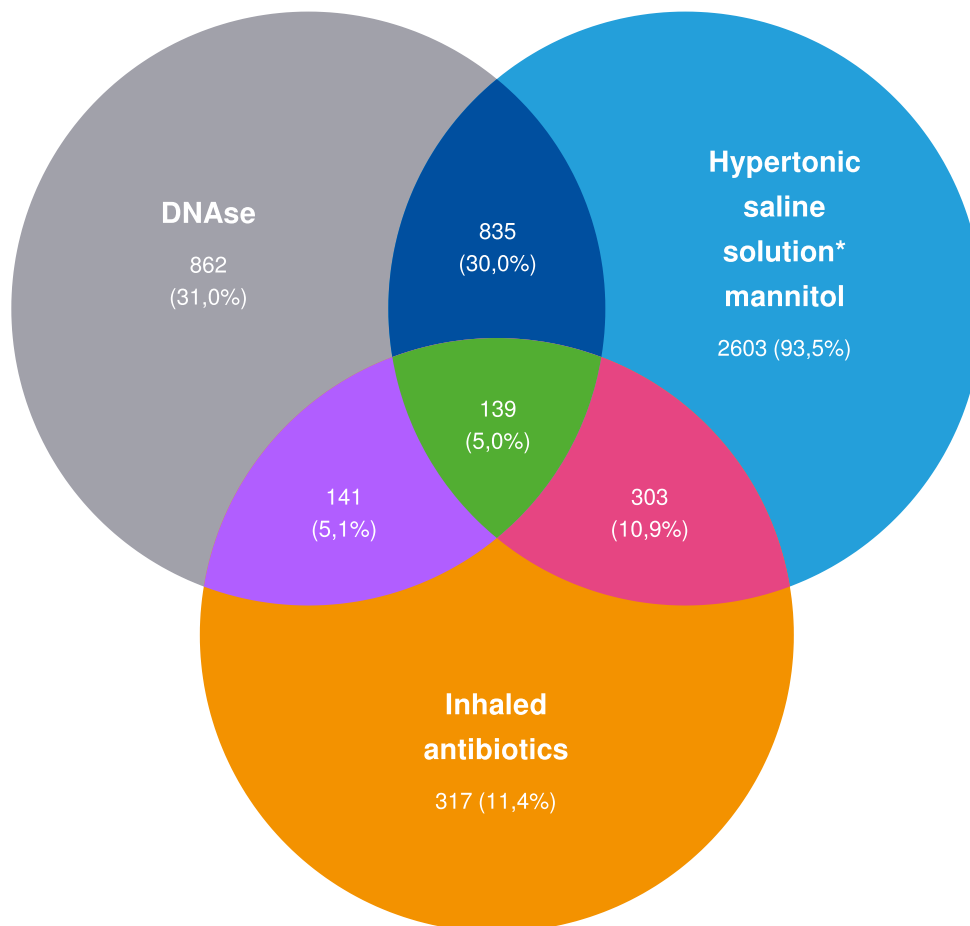


Fig. 35: Inhalation and combination therapies in people with CF under 18 years 2024 * Hypertonic saline solution (≥ 3 %)

Therapies

9a. Children and adolescents under 18 years

9a.iii Development of basic therapy

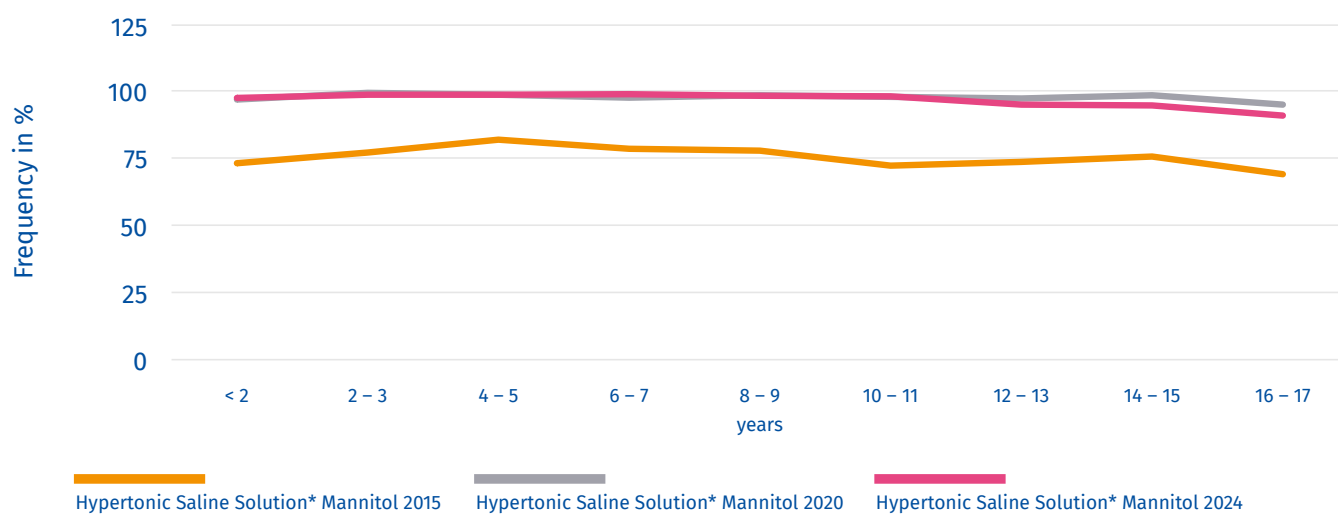


Fig. 36: Development of hypertonic saline solution ($\geq 3\%$) Mannitol in people with CF under 18 years 2015 – 2024

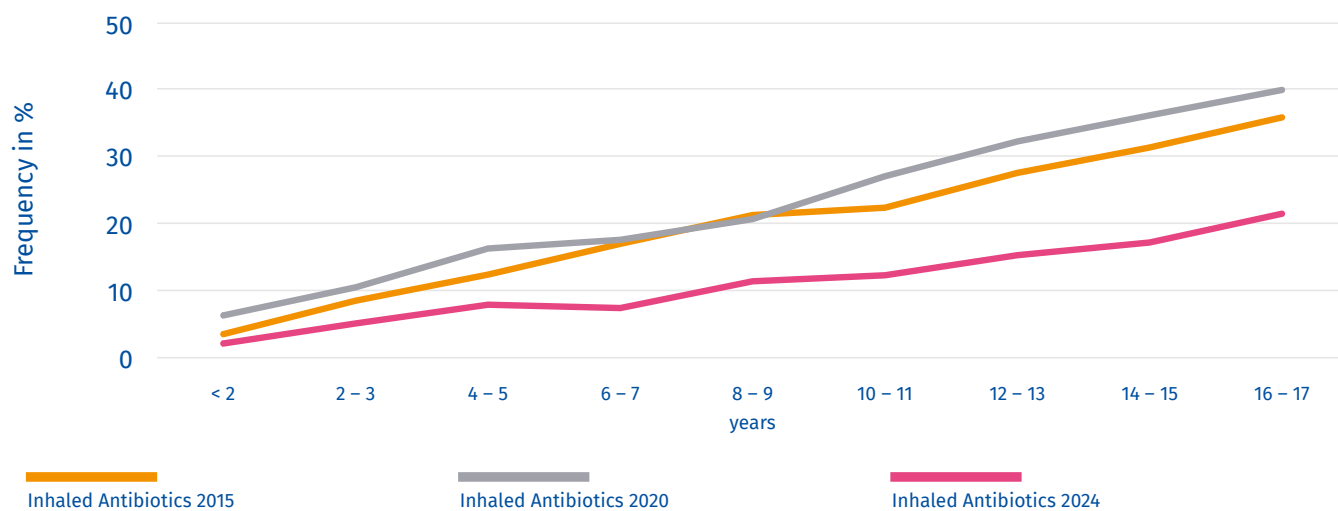


Fig. 37: Development of inhaled antibiotics in people with CF under 18 years 2015 – 2024

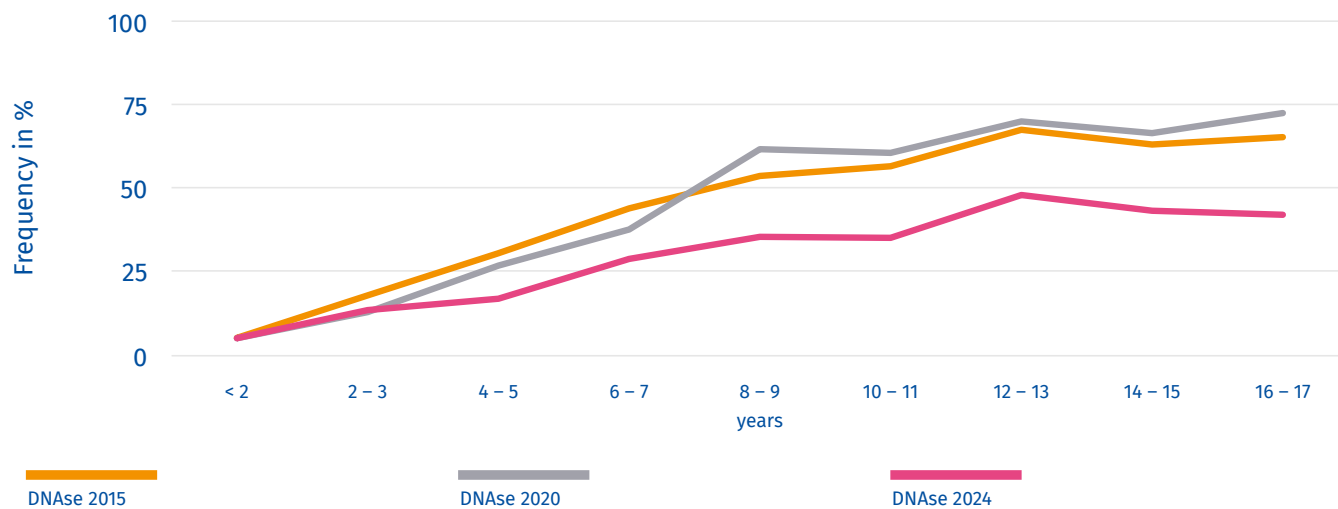


Fig. 38: Development of DNase in people with CF aged 18 and over 2015 – 2024

Therapies

9a. Children and adolescents under 18 years

9a.iv Indication therapy

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modulators on page 59

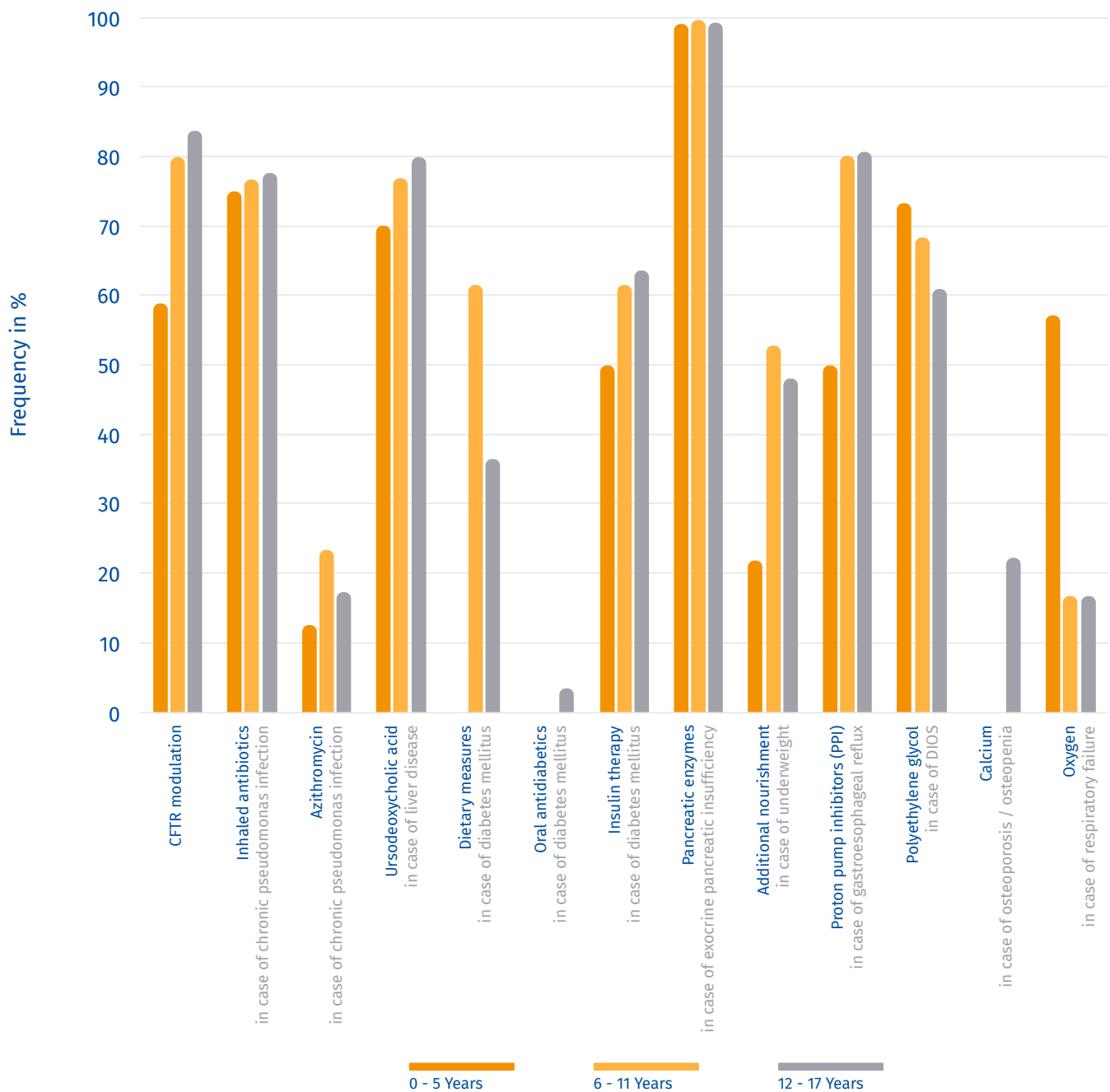


Fig. 39: People with CF under 18 years with indication therapy 2024



9a. Children and adolescents under 18 years

9a.iv Indication therapy

INDICATION THERAPY	AGE IN YEARS			
	0 - 5	6 - 11	12 - 17	TOTAL
CFTR modulation	58,9	79,9	83,6	75,1
of which Ivacaftor ¹	2,0	2,0	2,5	2,2
of which Lumacaftor / Ivacaftor ²	7,8	2,3	0,6	3,3
of which Tezacaftor / Ivacaftor ³	0,0	0,0	0,3	0,1
of which Elexacaftor / Tezacaftor / Ivacaftor ⁴	49,1	74,6	79,8	69,0
of which Vanzacaftor / Tezacaftor / Deutivacaftor	0,0	0,0	0,0	0,0
Inhaled antibiotics	75,0	76,6	77,6	77,1
in case of chronic pseudomonas infection				
of which inh. tobramycin	50,0	58,3	52,6	54,2
of which inh. colistin	66,7	72,2	65,8	67,8
of which inh. aztreonam	0,0	5,6	13,2	10,2
of which DPI-tobramycin	0,0	0,0	9,2	5,9
of which DPI-colistin	0,0	11,1	11,8	11,0
of which levofloxacin	0,0	0,0	0,0	0,0
of which wet inh. gentamicin	0,0	0,0	0,0	0,0
of which others	0,0	5,6	1,3	2,5
Azithromycin	12,5	23,4	17,3	19,0
in case of chronic pseudomonas infection				
Ursodeoxycholic acid	70,1	76,9	79,9	77,7
in case of liver disease				
Dietary measures	0,0	61,5	36,5	39,0
in case of diabetes mellitus				
Insulin therapy	50,0	61,5	63,5	63,0
in case of diabetes mellitus				
Oral antidiabetics	0,0	0,0	3,5	3,0
in case of diabetes mellitus				
Pancreatic enzymes	99,0	99,7	99,2	99,3
in case of exocrine pancreatic insufficiency				
Additional nourishment	21,9	52,8	48,0	40,8
in case of underweight				
Oral nutritional supplement	20,4	48,6	42,4	37,1
PEG	0,7	2,8	3,2	2,2
Proton pump inhibitors (PPI)	50,0	80,0	80,6	74,5
in case of gastroesophageal reflux				
Polyethylene glycol	73,3	68,4	60,9	66,7
in case of DIOS				
Calcium	0,0	0,0	22,2	16,7
in case of osteoporosis / osteopenia				
Oxygen	57,1	16,7	16,7	31,6
in case of respiratory failure				

Table 30: People with CF with indication therapy (frequencies in %) 2024

Therapies

9b. Adults from 18 years

9b.i Basic therapy

All patients without transplantation who answered the question about gastrointestinal or pulmonary long-term therapy were included in the evaluation of basic therapy. Datasets from 4.239 patients aged 18 and over were included in the analyses. For 2 patients (0.0 %), the question about gastrointestinal or pulmonary long-term therapy was not answered.

BASIC THERAPY	AGE IN YEARS					TOTAL
	18 - 29	30 - 39	40 - 49	50 - 59	≥ 60	
DNase	41,9	35,7	35,6	35,8	37,5	38,4
Mannitol	1,8	4,3	4,0	4,1	0,9	3,1
Hypertonic saline solution (≥ 3 %)	78,7	66,6	64,3	61,6	58,0	70,8
of which 3 – 5.7 %	18,0	23,1	23,3	21,2	35,4	20,8
of which ≥ 5.8 %	82,0	76,9	76,7	78,8	64,6	79,2
At least one mucolytic therapy (mannitol, DNase, hypertonic saline solution ≥ 3 %)	84,3	76,8	76,0	73,0	75,0	79,6
Short-acting β2-sympathomimetics (SABA)	58,9	52,1	60,0	60,8	57,1	57,1
Long-acting β2-sympathomimetics (LABA)	32,4	53,1	64,0	69,8	62,5	47,5
Anticholinergics	25,5	42,5	55,9	65,4	58,9	39,6
Anti-staphylococcal therapy	6,0	4,1	1,8	2,9	0,0	4,3
Nasal steroids	19,8	22,2	22,4	21,8	15,2	21,0
Inhaled steroids	26,4	41,9	51,0	52,3	58,0	38,0
Oral steroids	2,5	4,1	5,4	10,2	11,6	4,3
Vitamin A	73,2	65,2	61,5	60,2	40,2	67,0
Vitamin D	94,2	92,5	92,1	94,2	87,5	93,2
Vitamin E	73,3	64,5	60,7	60,5	40,2	66,7
Vitamin K	69,7	63,3	60,0	60,2	42,9	64,7
Hormonal contraception in women (collected from age 14)	30,8	21,3	16,6	3,8	5,4	23,0

Table 31: People with CF aged 18 and over with basic therapy (frequencies in %) 2024

Therapies

9b. Adults from 18 years

9b.ii Inhalation and combination therapies

In the graph for inhalation and combination therapies, all adults who answered the question about pulmonary long-term therapy were included (4.240 patients). 606 patients (14.3 %) of these received no inhalation therapy.

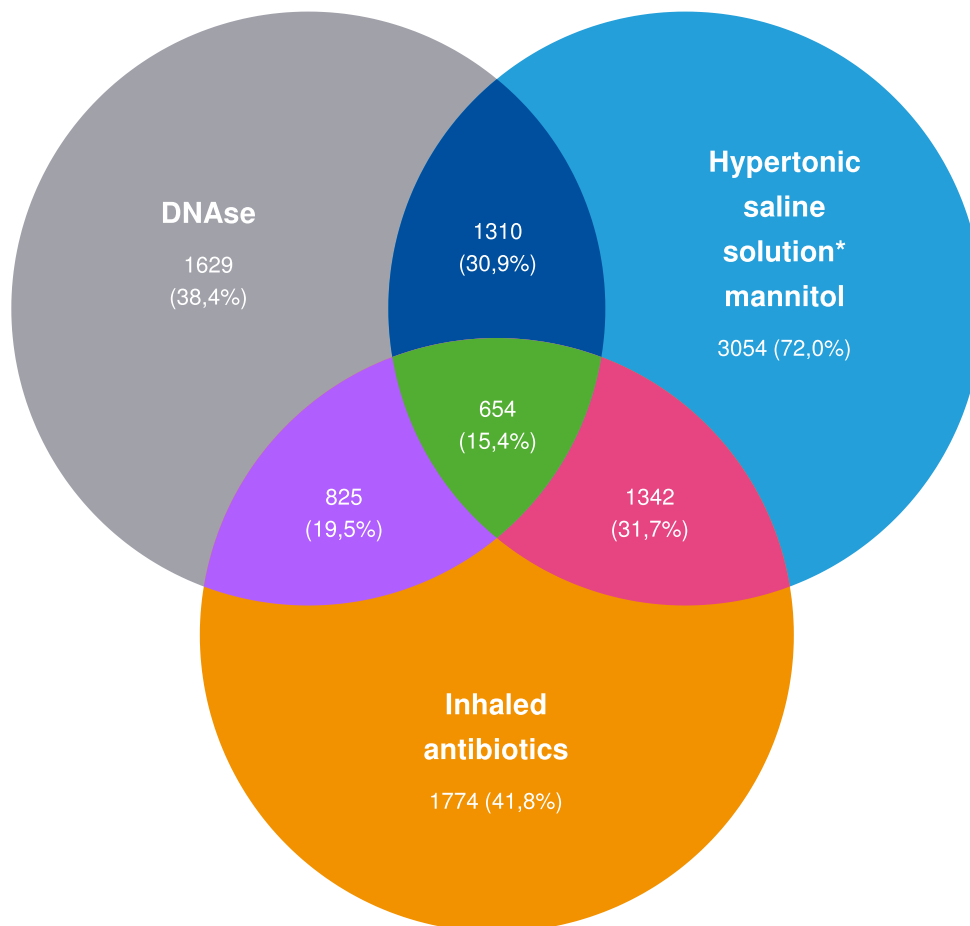


Fig. 33: Inhalation and combination therapies in people with CF aged 18 and over 2024 * Hypertonic saline solution (≥ 3 %)

Therapies

9b. Adults from 18 years

9b.iii Development of basic therapy

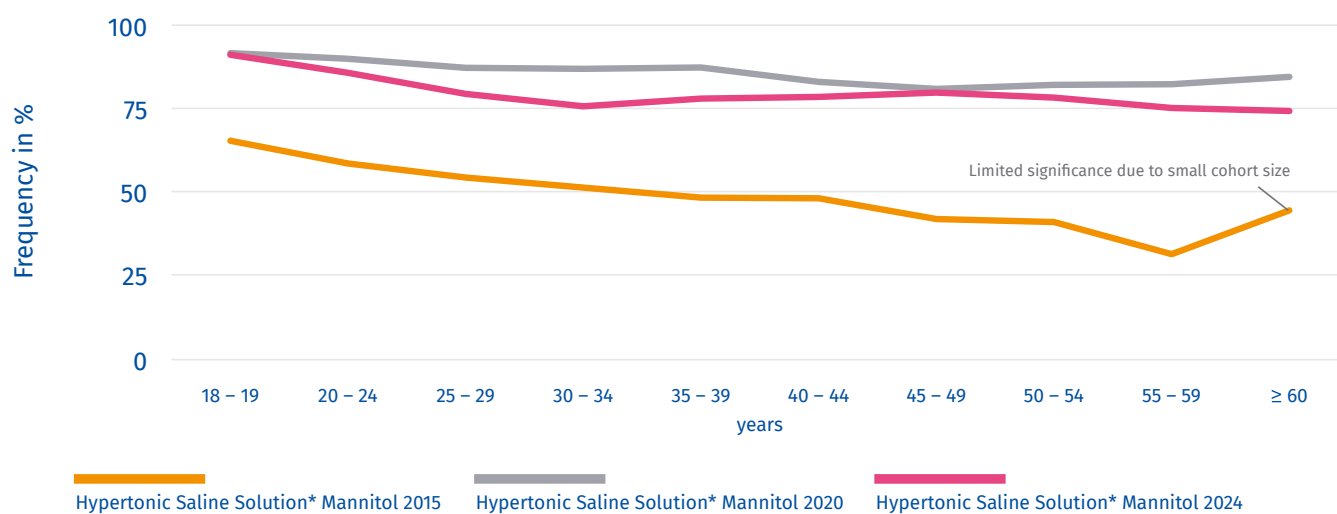


Fig. 41: Development of hypertonic saline solution (≥ 3 %) Mannitol in people with CF aged 18 and over 2015 – 2024

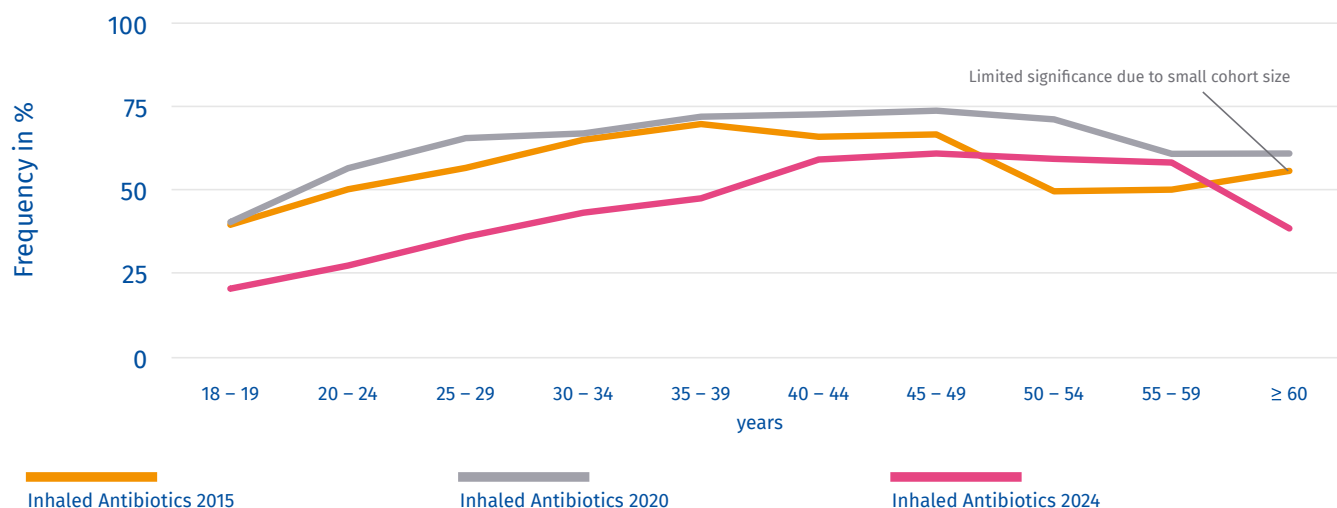


Fig. 42: Development of inhaled antibiotics in people with CF aged 18 and over 2015 – 2024

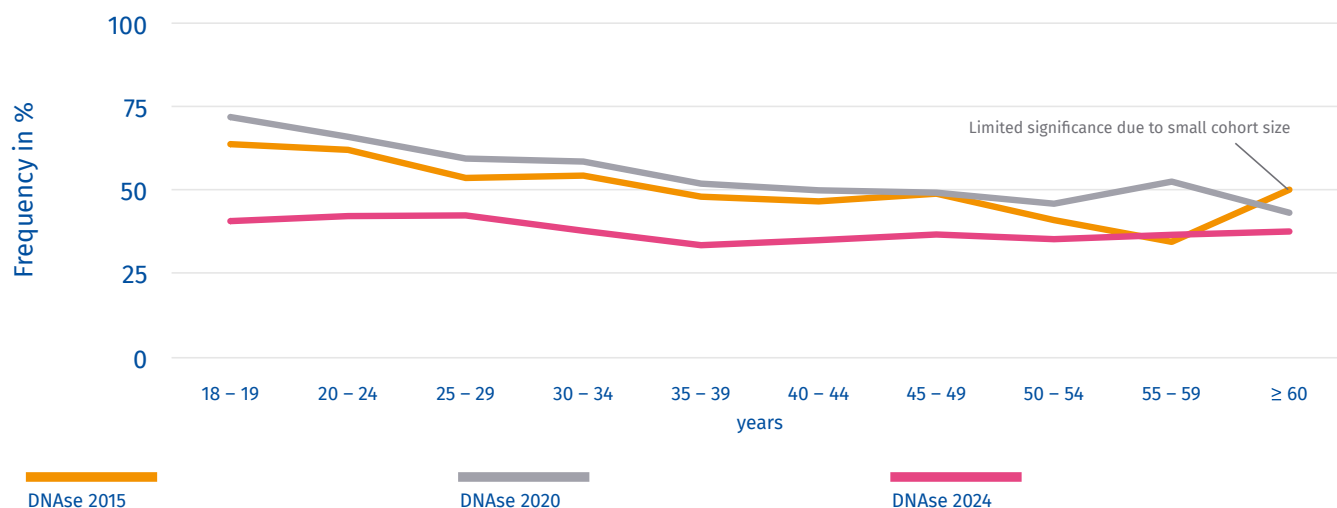


Fig. 43: Development of DNase in people with CF 2015 – 2024

Therapies

9b. Adults from 18 years

9b.iv Indication therapy

Approval status of CFTR modulators on page 59

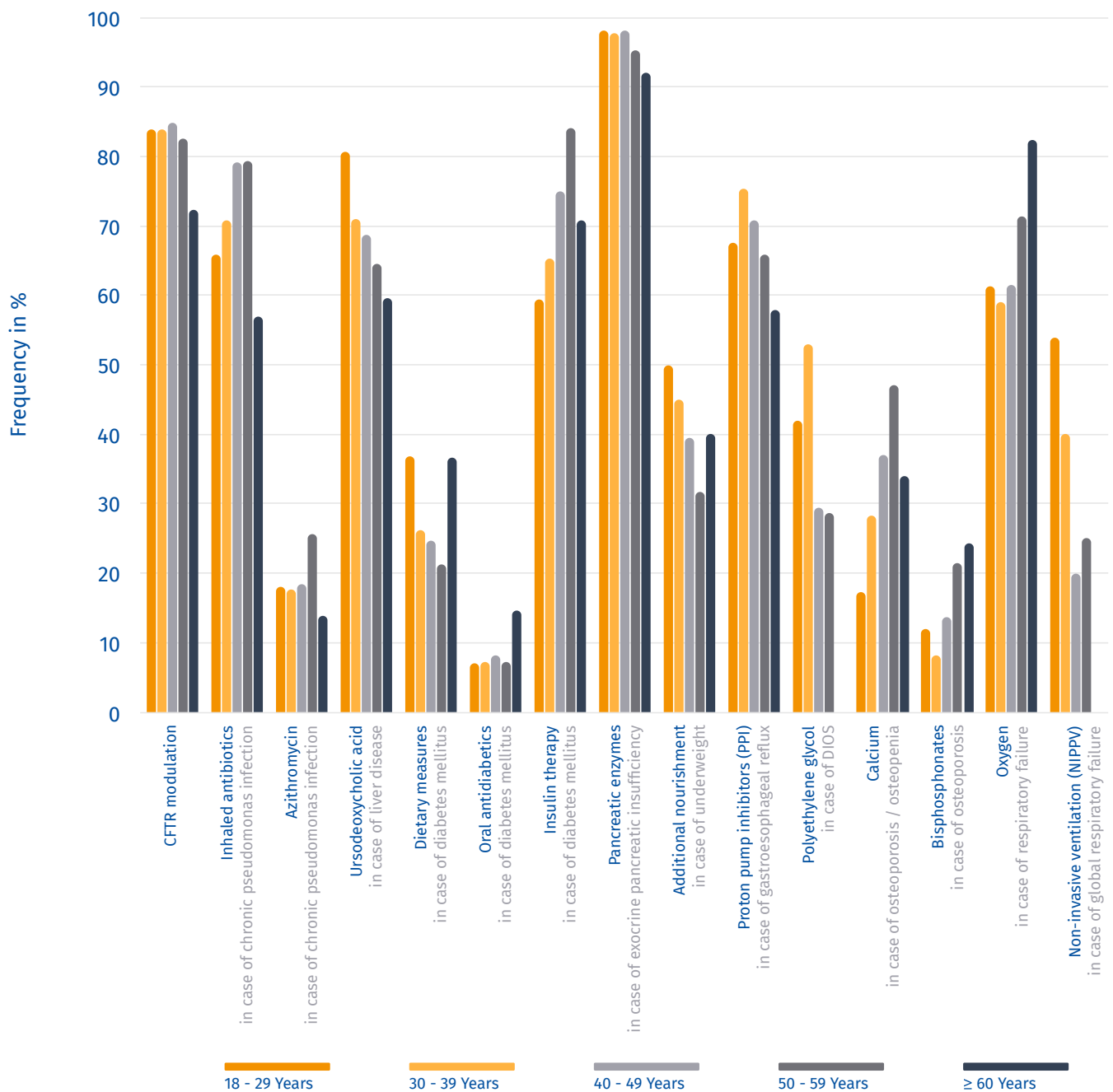


Fig. 44: People with CF over 18 years with indication therapy 2024

9b. Adults from 18 years

9b.iv Indication therapy

Approval status of CFTR
modulators on page 59

INDICATION THERAPY	AGE IN YEARS					TOTAL
	18 - 29	30 - 39	40 - 49	50 - 59	≥ 60	
CFTR modulation	83,9	83,9	84,8	82,6	72,3	83,6
of which Ivacaftor ¹	2,0	1,9	1,8	2,9	4,5	2,1
of which Lumacaftor / Ivacaftor ²	0,1	0,2	0,0	0,0	0,0	0,1
of which Tezacaftor / Ivacaftor ³	1,3	0,5	1,8	0,9	2,7	1,2
of which Elexacaftor / Tezacaftor / Ivacaftor ⁴	80,1	80,3	80,6	78,2	64,3	79,7
of which Vanzacaftor / Tezacaftor / Deutivacaftor	0,1	0,2	0,1	0,0	0,0	0,1
Inhaled antibiotics	65,8	70,7	79,2	79,4	56,9	71,9
in case of chronic pseudomonas infection						
of which inh. tobramycin	36,2	29,9	21,1	18,2	9,1	27,3
of which inh. colistin	61,5	55,4	61,0	61,8	66,7	59,5
of which inh. aztreonam	23,2	32,4	36,3	37,6	33,3	31,7
of which DPI-tobramycin	15,9	15,1	11,0	5,3	0,0	12,6
of which DPI-colistin	18,5	16,0	17,0	11,8	15,2	16,3
of which levofloxacin	9,1	12,2	18,2	22,9	18,2	14,4
of which wet inh. gentamicin	0,0	0,2	0,0	0,0	0,0	0,1
of which others	2,1	2,4	3,3	4,7	0,0	2,8
Azithromycin	18,0	17,6	18,4	25,7	13,8	18,7
in case of chronic pseudomonas infection						
Ursodeoxycholic acid	80,7	71,0	68,7	64,5	59,5	74,3
in case of liver disease						
Dietary measures	36,9	26,1	24,7	21,3	36,6	29,0
in case of diabetes mellitus						
Insulin therapy	59,3	65,3	74,9	84,1	70,7	68,0
in case of diabetes mellitus						
Oral antidiabetics	7,0	7,3	8,1	7,3	14,6	7,6
in case of diabetes mellitus						
Pancreatic enzymes	98,1	97,7	98,1	95,3	92,0	97,6
in case of exocrine pancreatic insufficiency						
Additional nourishment	50,0	45,0	39,4	31,6	40,0	46,2
in case of underweight						
Oral nutritional supplement	42,7	42,5	36,4	26,3	40,0	40,9
PEG	2,4	2,5	0,0	5,3	0,0	2,3
Proton pump inhibitors (PPI)	67,6	75,3	70,7	65,9	57,9	69,4
in case of gastroesophageal reflux						
Polyethylene glycol	42,0	52,9	29,4	28,6	0,0	42,6
in case of DIOS						
Calcium	17,3	28,2	37,0	47,0	33,9	31,0
in case of osteoporosis / osteopenia						
Bisphosphonates	12,0	8,2	13,7	21,5	24,2	14,3
in case of osteoporosis						
Oxygen	61,2	59,1	61,5	71,4	82,4	63,8
in case of respiratory failure						
Non-invasive ventilation (NIPPV)	53,8	40,0	20,0	25,0	0,0	34,0
in case of global respiratory failure						

Table 32: People with CF with indication therapy (frequencies in %) 2024

Therapies

9c. CFTR Modulators

9c.i Approval status of CFTR modulators



Approval status of CFTR modulators 31.12.2024

Only the last used modulator in the report year is shown here.

- 1 Ivacaftor has been approved since 2018 from the age of 1 year and since 2020 from 4 months for patients with mutations G551D, G1244E, G1349D, G178R, G551S, S1251N, S1255P, S549N or S549R. For patients with the mutation R117H, Ivacaftor has been approved since 2018 from 18 years, since 2020 also from 4 months.
- 2 Lumacaftor/Ivacaftor has been approved for F508del homozygous patients since 2018 from 6 years, since 2019 from the age of 2 years and since July 2023 from 1 year.
- 3 Tezacaftor/Ivacaftor has been approved since 2019 from 12 years for F508del homozygous patients or for F508del heterozygous patients with one of the following mutations: P67L, R117C, L206W, R352Q, A455E, D579G, 711+3A->G, S945L, S977F, R1070W, D1152H, 2789+5G->A, 3272-26A->G and 3849+10kbC->T.
- 4 Elexacaftor/Tezacaftor/Ivacaftor has been approved since 2020 from 12 years for F508del homozygous patients or F508del heterozygous patients with a minimal function (MF) mutation, since 2021 for all patients from 12 years, since 2022 from 6 years and since November 2023 from 2 years with at least one F508del mutation. Intake of Elexacaftor/Tezacaftor/Ivacaftor before 2020 was possible within clinical trials.

Therapies

9c. CFTR Modulators

Approval status of CFTR modulators on page 59



9c.ii Development of CFTR modulator therapy 2018 – 2024

For the representation of CFTR modulator therapy, all patients without transplantation taking a modulator or all patients for whom a suitable modulator is approved in the respective report year were considered.

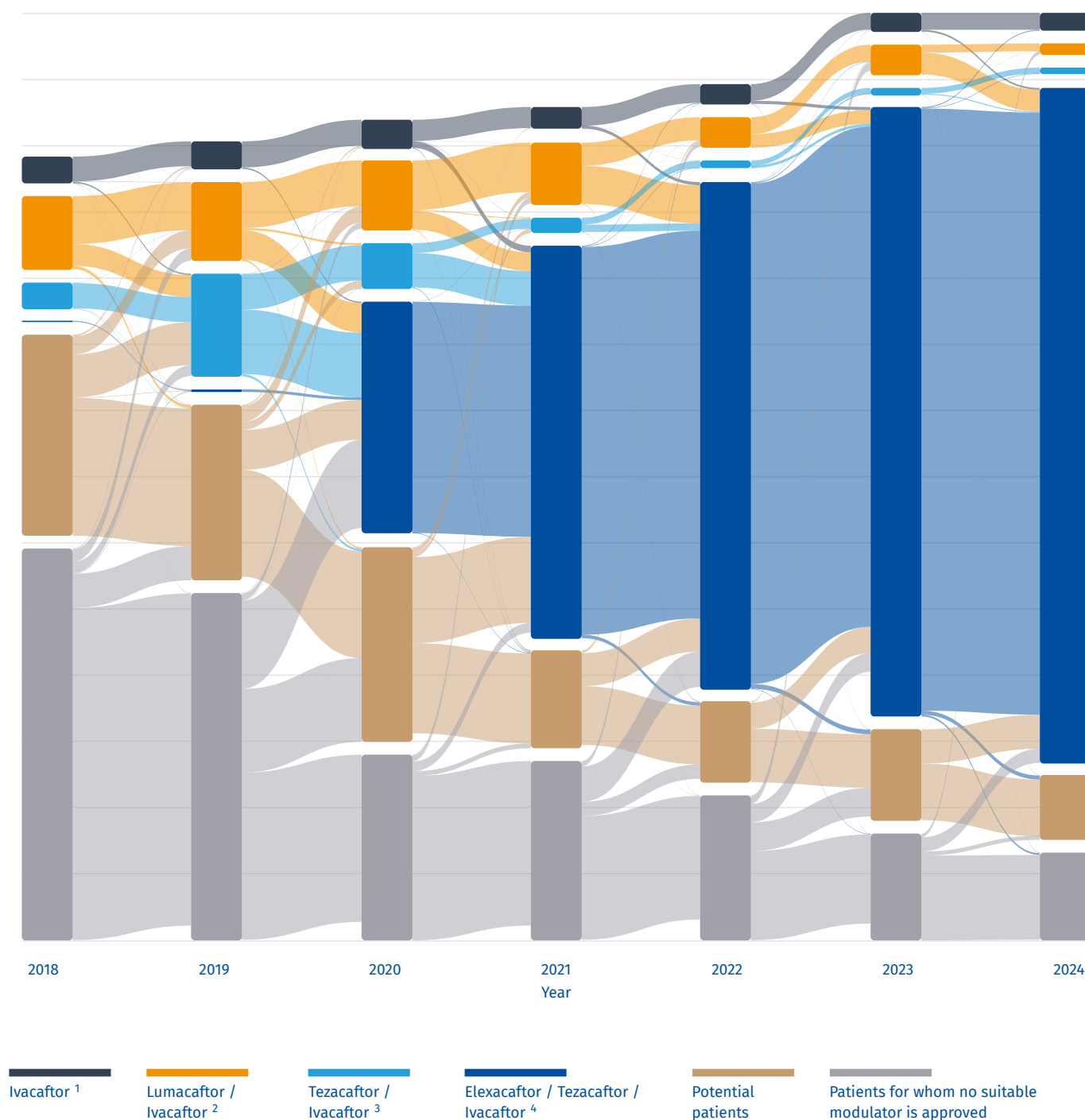


Fig. 45: Number of people with CF with a modulator therapy and number of patients for whom a suitable modulator is approved or not approved 2018 – 2024

Mortality

10a. Age at death

Lifetime is described by the median age of death, the median survival and the average age-specific life expectancy. The current median age of death is reported for year 2024, while median survival and life expectancy refer to a 5-year period (e.g. 2020 – 2024).

Median age of death

The median age of death describes the age of the deceased for a fixed year at which half of the patients have deceased. In the report year 2024 (2023), the median age of death is 43 (39) years.

In report year 2024, 40 patients (19 girls/women and 21 boys/men) deceased. Main causes of death were cardiopulmonary diseases (27,5 %), malignant diseases (15,0 %), Transplantation (5,0 %) and Liver disease (5,0 %). In 47,5 % of cases, other or unknown causes were present. The age at death is distributed as follows:

	NUMBER	AVERAGE	MEDIAN	MINIMUM	MAXIMUM	25TH PERCENTILE	75TH PERCENTILE
Age at death in full years	40	42,8	43,0	9	71	31,5	54,0

Table 33: Age at death 2024

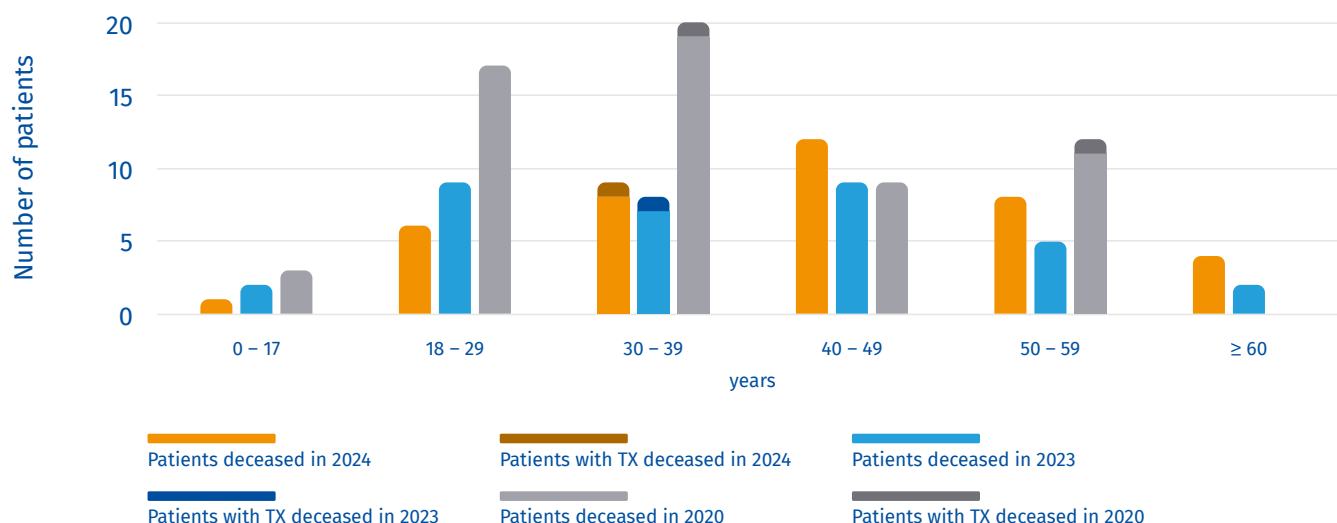


Fig. 46: People with CF deceased in years 2020 – 2024

AGE	2020				2023				2024			
	TX		NO TX		TX		NO TX		TX		NO TX	
	NUMBER	%	NUMBER	%	NUMBER	%	NUMBER	%	NUMBER	%	NUMBER	%
0 – 17	3	100,0	0	0,0	2	100,0	0	0,0	1	100,0	0	0,0
18 – 29	17	100,0	0	0,0	9	100,0	0	0,0	6	100,0	0	0,0
30 – 39	19	95,0	1	5,0	7	87,5	1	12,5	8	88,9	1	11,1
40 – 49	9	100,0	0	0,0	9	100,0	0	0,0	12	100,0	0	0,0
50 – 59	0	0,0	0	0,0	5	100,0	0	0,0	8	100,0	0	0,0
≥ 60	11	91,7	1	8,3	2	100,0	0	0,0	4	100,0	0	0,0
Total	59	-	2	-	34	-	1	-	39	-	1	-

Table 34: Deceased people with CF 2020 – 2024

Mortality

10b. Median predicted survival age

The calculation of the median predicted survival age and also the median predicted life expectancy shown on the next tab is based on the number of people with Cystic Fibrosis documented in the registry as living / deceased in the respective year and does not take into account the possible effects of CFTR modulator therapies and other advances in clinical care. In recent years, annual deaths have declined sharply, resulting in lower precision in predicting survival age and life expectancy. This is also reflected in the form of wider confidence intervals in the predictions.

Median predicted survival age 2023

The median predicted survival age describes the expected age up to which half of the patients born between 2019 and 2023 will live. To compensate for fluctuations in the calculation of the median predicted survival age due to the annually different number of deaths, a COX PH regression analysis is performed in a 5-year period according to Sykes (Journal of Clinical Epidemiology 2016; 70: 206). In the 5-year window from 2019 – 2023, 8346 people with Cystic Fibrosis (incl. transplanted patients) and 251 deaths were recorded. The proportion of patients lost to follow-up was 471 (5,6 %). Median survival was 65,0 years (confidence interval: 60,4 to 79,0).

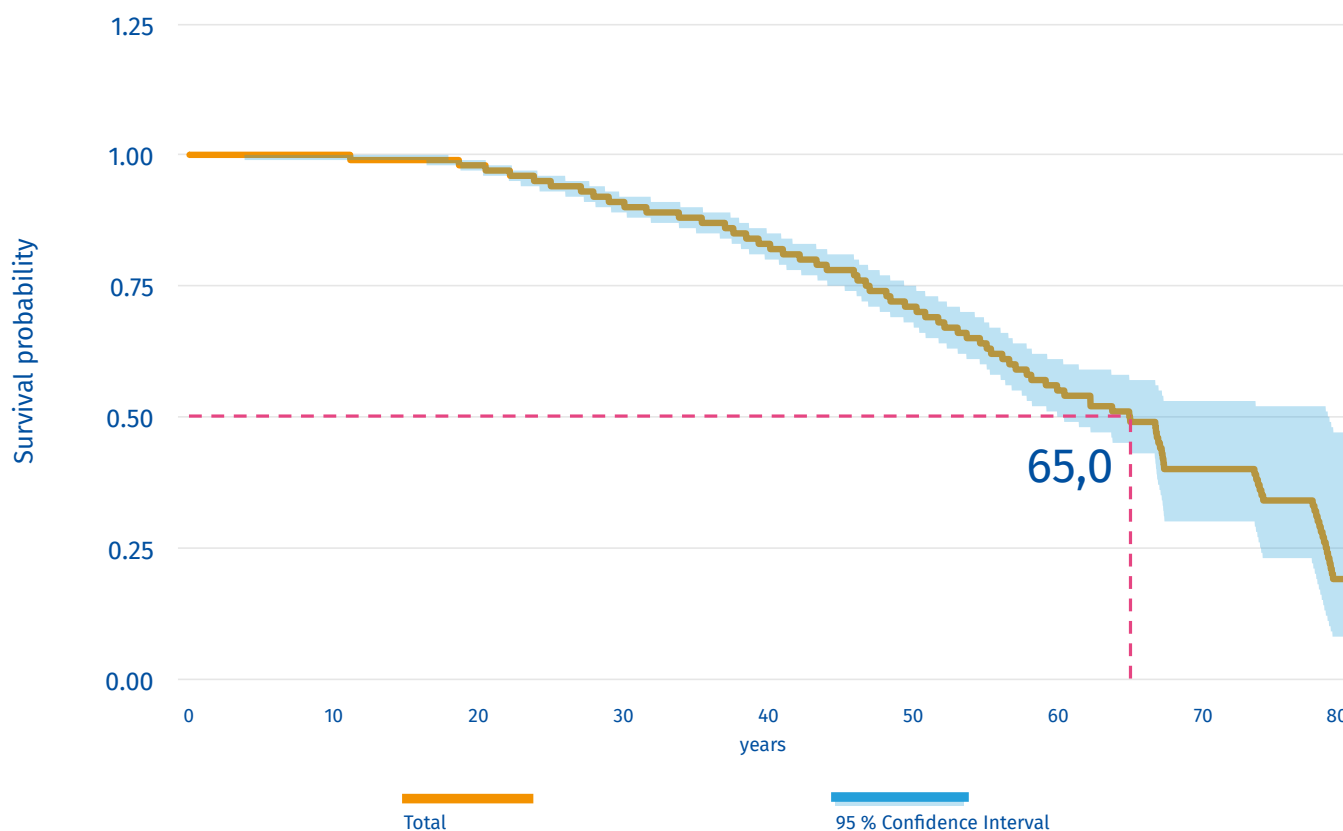


Fig. 47: Median survival age for people with CF for the period 2019 – 2023

Mortality

10b. Median predicted survival age

Median predicted survival age 2024

The median predicted survival age describes the expected age up to which half of the patients born between 2020 and 2024 will live. To compensate for fluctuations in the calculation of the median predicted survival age due to the annually different number of deaths, a COX PH regression analysis is performed in a 5-year period according to Sykes (Journal of Clinical Epidemiology 2016; 70: 206). In the 5-year window from 2020 – 2024, 8456 people with Cystic Fibrosis (incl. transplanted patients) and 228 deaths were recorded. The proportion of patients lost to follow-up was 493 (5,8 %). Median survival was 66,8 years (confidence interval: 63,8 to 71,7).

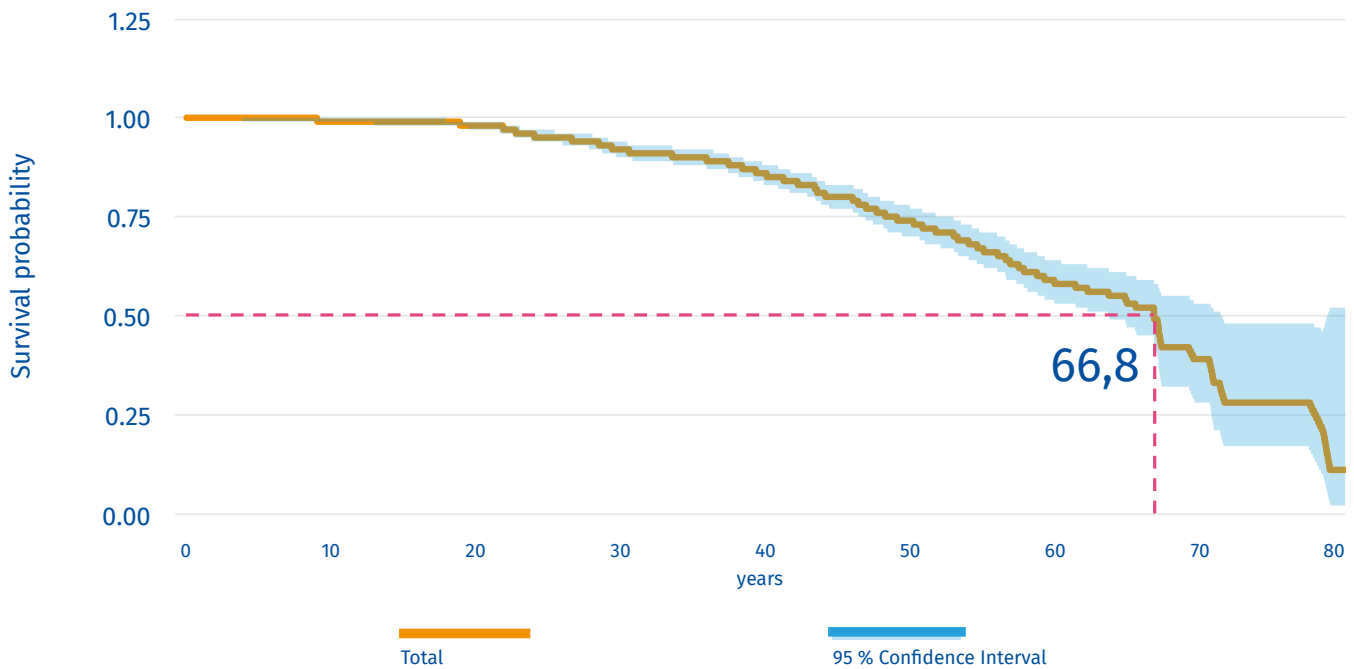


Fig. 48: Median survival age for people with CF for the period 2020 – 2024

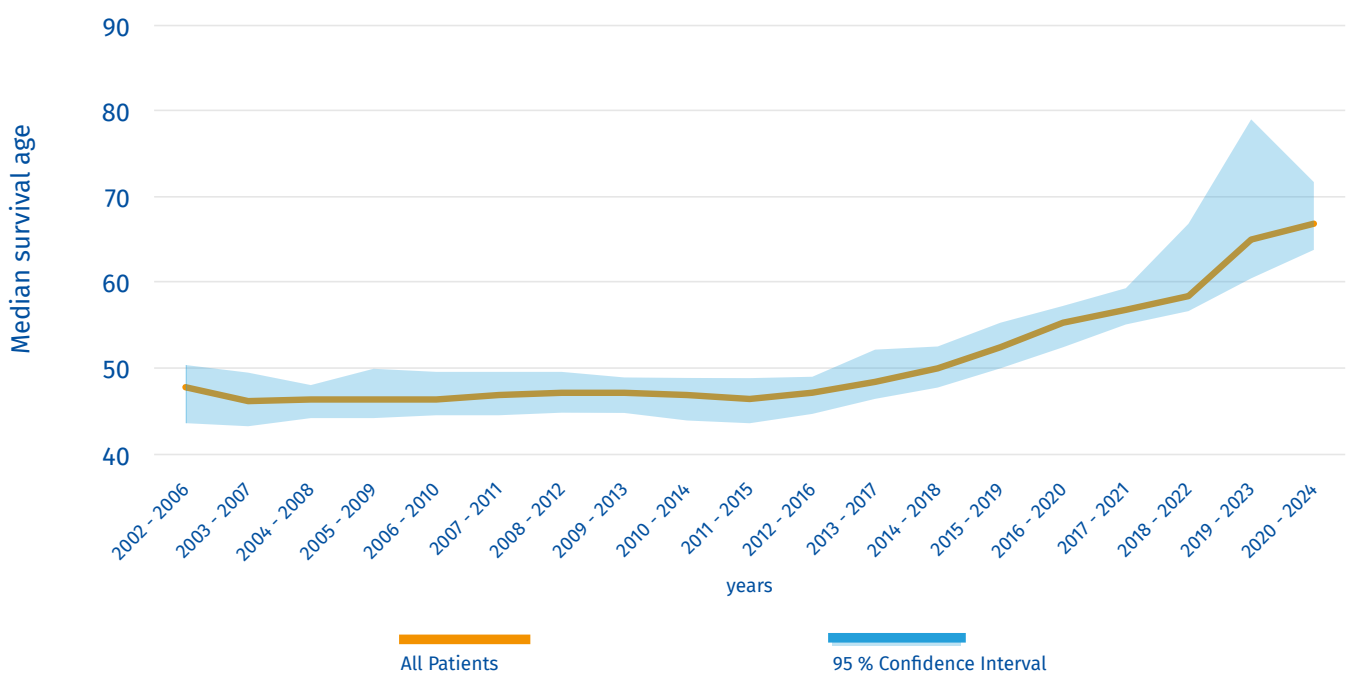


Fig. 49: Median predicted survival age over the years

Mortality

10c. Life expectancy

Life expectancy is the average time expected for a person from a certain age until death. It is calculated for a fixed period and is based on current and age-specific death rates. 2023 the life expectancy of a healthy male newborn in Germany is 78,5 years, that of a female newborn 83,2 years (<https://de.statista.com/statistik/daten/studie/1783/umfrage/durchschnittliche-weitere-lebenserwartung-nach-altersgruppen/>). Life expectancy is different for each age and does not correspond to the median survival age.

All indicators refer to the individually very different population of people with CF in Germany. They therefore only allow limited conclusions for individuals. Important influencing factors according to literature include gender, the present gene mutation and exocrine pancreatic function. All calculations are based on the current rate of deaths, which has fortunately decreased steadily in the past.

Life expectancy 2023

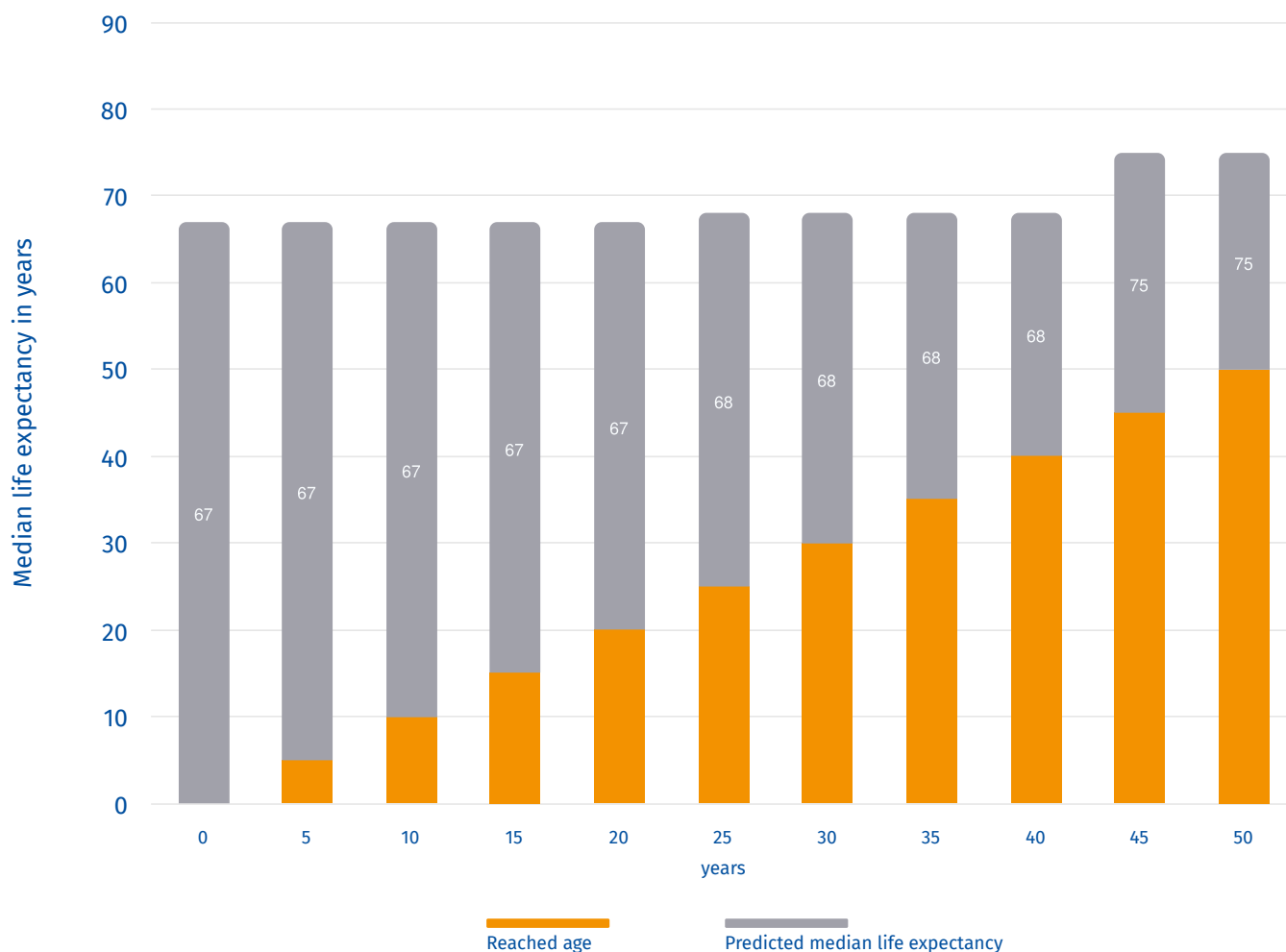


Fig. 50: Predicted median life expectancy for people with CF 2019 – 2023

Mortality

10c. Life expectancy

Life expectancy 2024

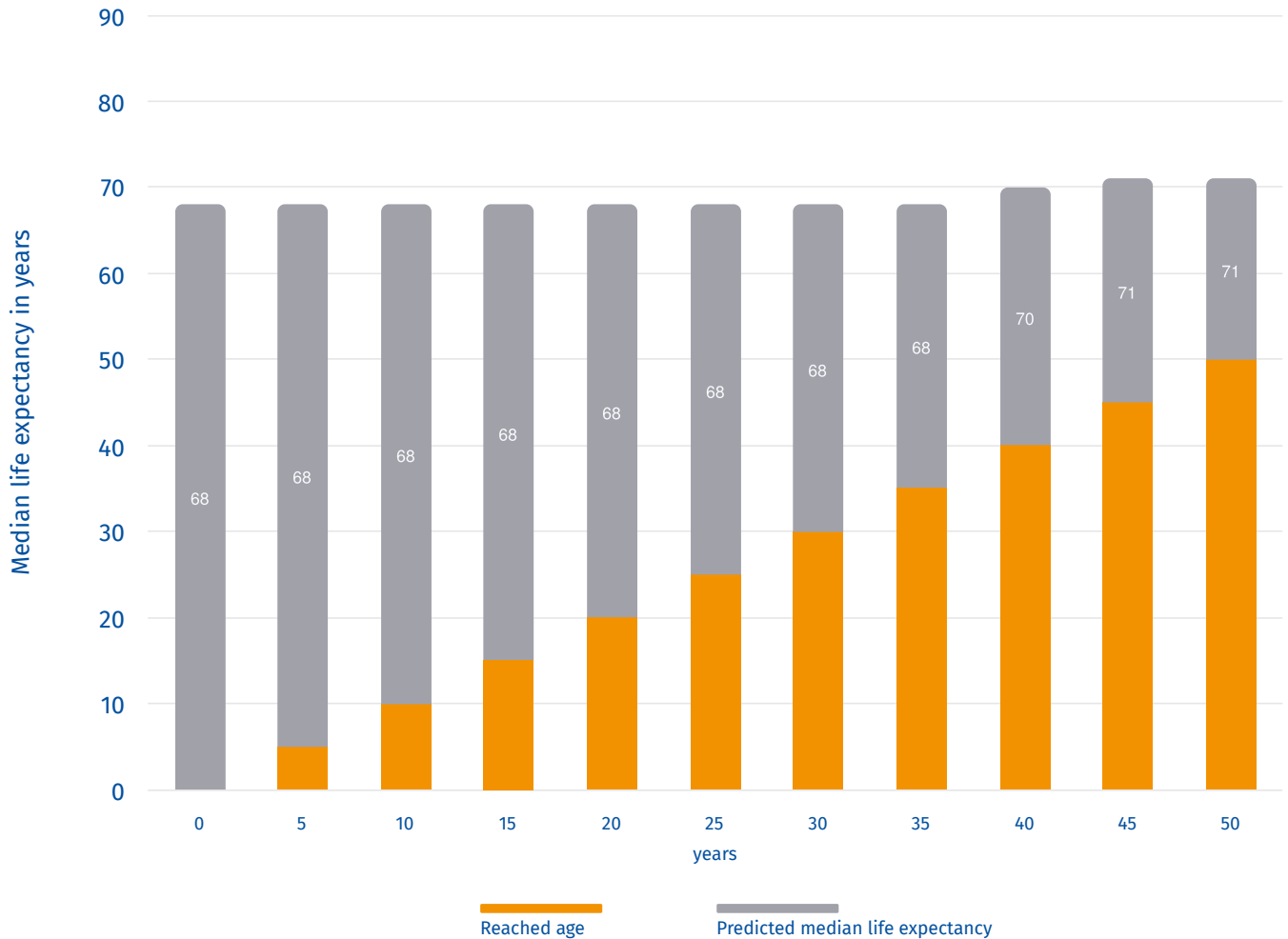


Fig. 51: Predicted median life expectancy for people with CF 2020 – 2024

Structure of care

11a. Size of the participating facilities

In the report year 2024, 83 facilities participated in the Cystic Fibrosis Registry. 39 facilities cared for fewer than 50 patients and 44 facilities cared for more than 50 patients. More than 86 % of the patients documented in the registry are cared for in these facilities.

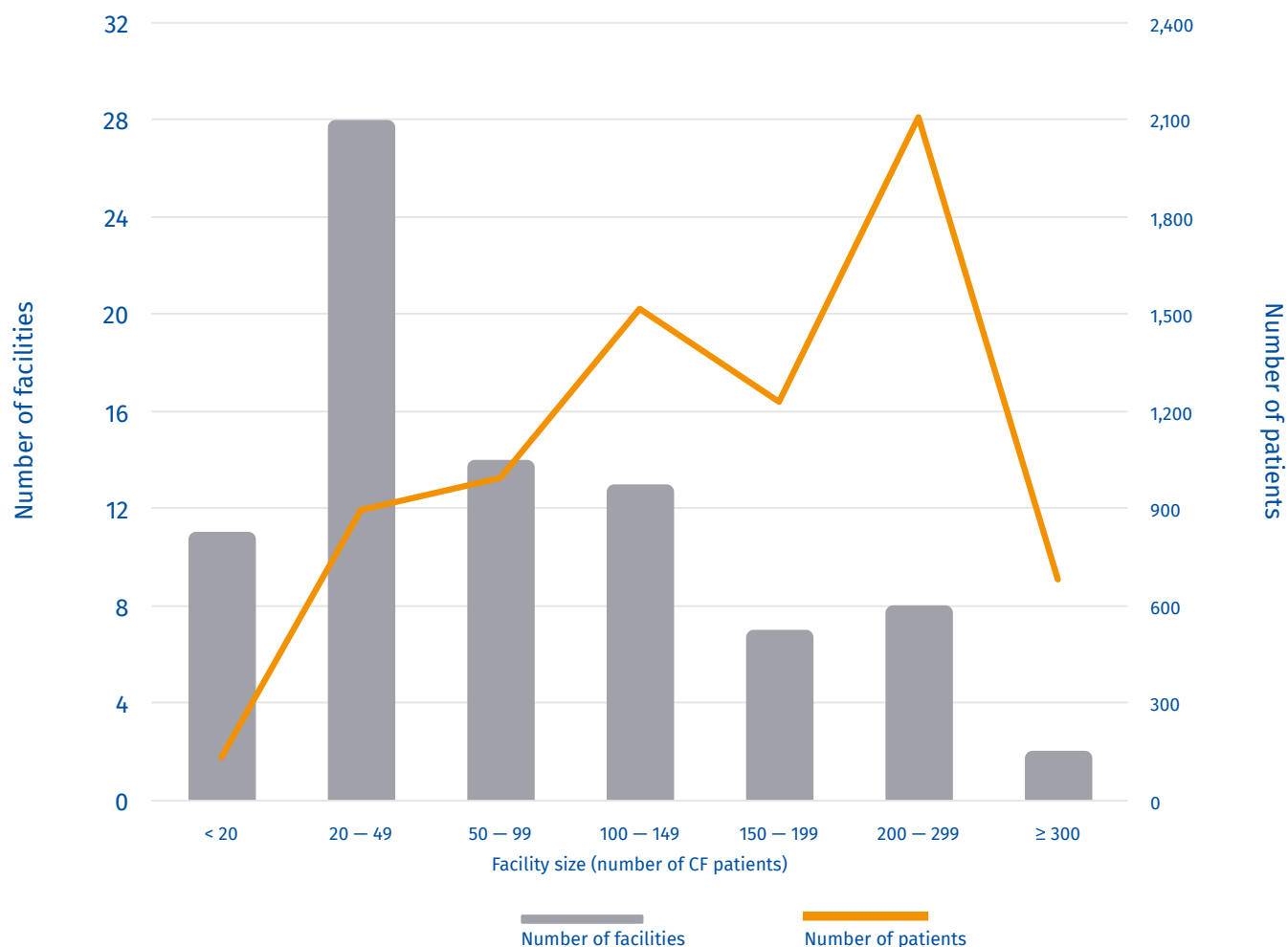


Fig. 52: Number of documented people with CF and number of facilities 2024

Structure of care

11b. Clinic care

All patients with history data in the year 2024 (n=7362) were included in the following analyses.

	AGE IN YEARS										TOTAL
	0 - 5	6 - 11	12 - 17	18 - 29	30 - 39	40 - 49	50 - 59	≥ 60	< 18	≥ 18	
Physiotherapy in the outpatient clinic	79,5	76,2	73,0	54,8	54,7	54,9	60,8	59,7	76,1	55,5	63,3
Nutritional therapy in the outpatient clinic	57,8	48,2	45,1	20,2	14,7	14,7	13,6	17,6	49,9	17,0	29,5
Psychosocial support in the outpatient clinic	46,7	45,6	45,7	31,5	23,2	23,5	23,1	35,3	46,0	27,0	34,2
Anxiety and depression screening¹	-	-	33,7	45,5	49,6	47,7	46,7	57,1	33,7	47,5	45,1
Imaging Thorax	52,0	53,8	51,9	45,0	42,5	43,2	48,7	60,5	52,6	44,7	47,7
Imaging Abdomen	64,4	67,3	66,5	53,8	53,8	52,1	58,5	60,5	66,2	54,1	58,7
Imaging Bone densitometry	0,0	1,3	4,8	10,2	12,7	15,0	16,7	20,2	2,1	12,6	8,6
Laboratory	95,8	95,8	95,5	96,0	96,6	96,4	97,7	100,0	95,7	96,5	96,2
Rehab stay	4,8	6,5	7,0	2,8	3,6	5,0	8,2	2,5	6,2	3,9	4,7
OGTT² in patients without diabetes mellitus in the previous year	-	13,8	50,4	31,3	23,6	17,3	14,6	20,2	31,5	24,9	26,9

Table 35: People with CF with clinic care (frequencies in %) 2024

¹ referring to people with CF aged 12 and over

² referring to people with CF aged 6 and over

Structure of care

11c. Cystic Fibrosis-relevant hospitalizations

Number of Cystic Fibrosis-relevant hospitalizations per patient (frequencies in %) 2024

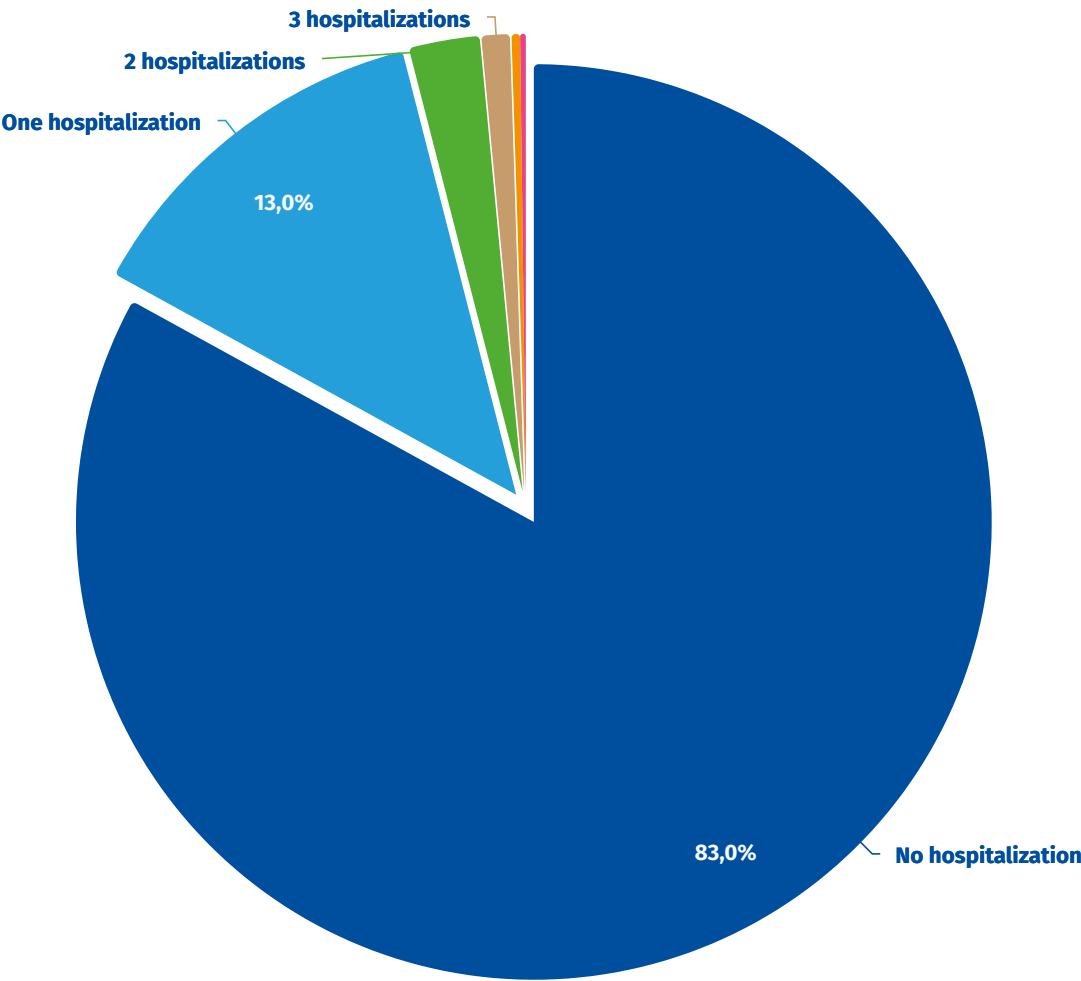


Fig. 53: Number of Cystic Fibrosis-relevant hospitalizations per patient (frequencies in %) 2024

NUMBER PER PATIENT	0 – 5	6 – 11	12 – 17	18 – 29	30 – 39	≥ 40	TOTAL	< 18	≥ 18
0	73,5	81,6	82,7	85,2	85,7	84,0	83,0	79,6	85,0
1	21,0	14,7	13,4	10,9	10,9	11,9	13,0	16,1	11,2
2	3,8	2,3	2,5	2,2	2,1	2,6	2,5	2,8	2,3
3	1,2	0,8	0,7	0,8	1,0	1,2	1,0	0,9	1,0
4	0,2	0,3	0,2	0,4	0,2	0,2	0,3	0,3	0,3
5+	0,1	0,3	0,5	0,4	0,1	0,0	0,2	0,3	0,2
unknown	0,0	0,0	0,0	0,0	0,0	0,0	0,0	0,0	0,0

Table 36: Number of Cystic Fibrosis-relevant hospitalizations per patient (frequencies in %) 2024

Structure of care

11c. Cystic Fibrosis-relevant hospitalizations

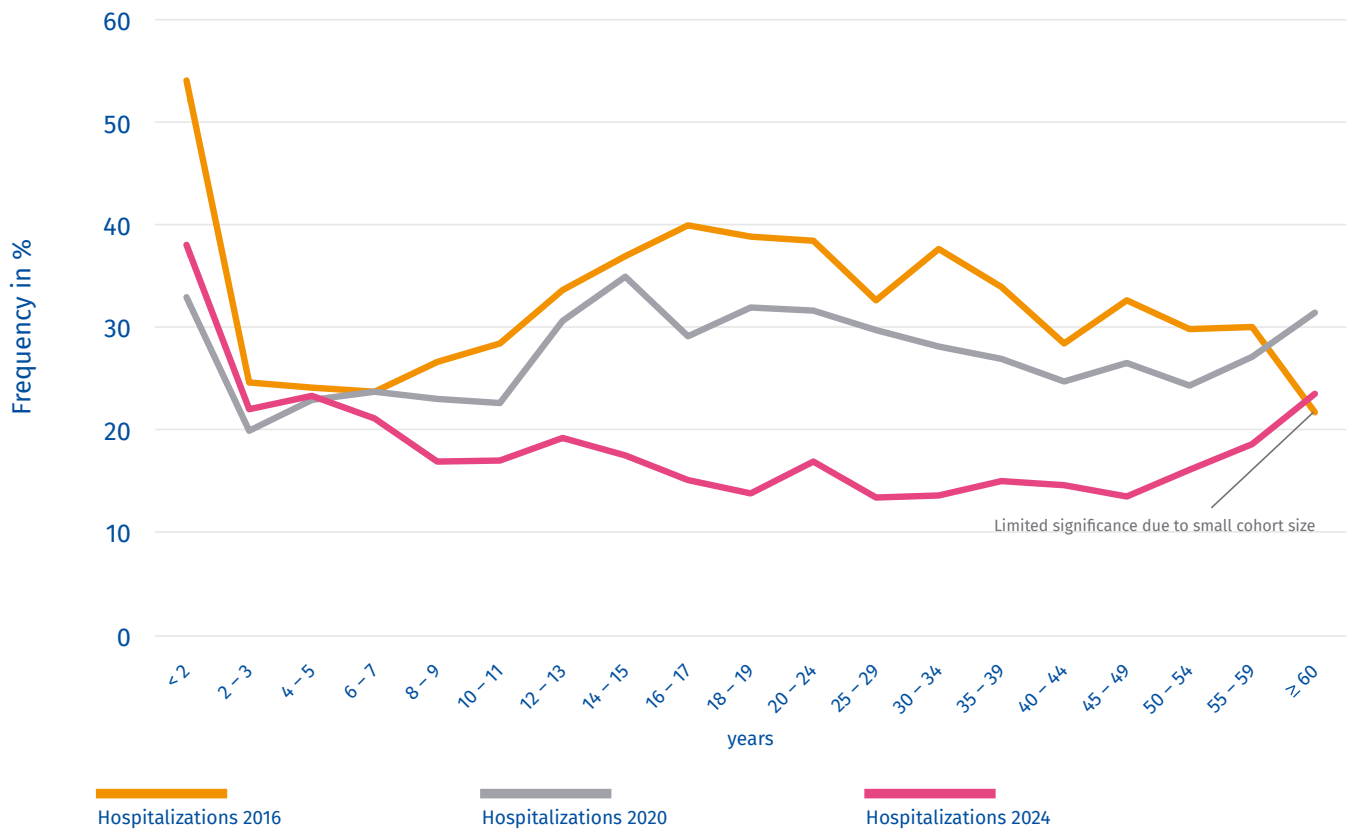


Fig. 54: Development of the proportion of people with CF with at least 1 hospitalization 2016 - 2024

YEAR	< 2	2 – 3	4 – 5	6 – 7	8 – 9	10 – 11	12 – 13	14 – 15	16 – 17	18 – 19	20 – 24	25 – 29	30 – 34	35 – 39	40 – 44	45 – 49	50 – 54	55 – 59	≥ 60
2024	38,0	22,0	23,3	21,1	16,9	17,0	19,2	17,5	15,1	13,8	16,9	13,4	13,6	15,0	14,6	13,5	16,1	18,6	23,5
2023	33,9	25,2	24,0	19,4	20,5	16,5	20,8	18,7	21,1	16,8	18,7	19,4	14,1	19,2	15,8	17,8	22,0	19,9	20,7
2022	26,7	21,7	23,0	18,7	20,9	20,6	17,9	22,0	21,9	15,9	20,8	22,0	15,0	18,9	18,6	19,5	20,0	15,4	25,6
2021	34,9	21,3	18,9	23,9	21,1	23,2	22,8	25,2	27,0	26,4	21,3	20,8	15,2	18,3	16,4	18,5	20,0	21,7	23,7
2020	32,9	19,9	22,9	23,7	23,0	22,6	30,6	34,9	29,1	31,9	31,6	29,7	28,1	26,9	24,7	26,5	24,3	27,1	31,4
2019	35,0	23,1	23,4	24,2	24,3	25,0	30,0	33,1	36,9	37,9	36,2	34,6	32,8	33,6	26,4	35,0	33,2	37,7	40,5
2018	31,8	23,2	25,6	21,1	26,0	25,5	29,8	29,3	42,9	40,1	35,9	32,1	32,3	31,0	33,1	32,3	25,1	43,1	30,3
2017	47,2	25,0	22,8	20,7	26,3	28,1	29,9	36,3	41,6	37,9	39,4	36,2	38,2	33,6	35,6	34,1	31,8	33,3	28,6
2016	54,0	24,6	24,1	23,7	26,6	28,4	33,6	36,9	39,9	38,8	38,4	32,6	37,6	33,9	28,4	32,6	29,8	30,0	21,7

Table 37: Development of age-related frequencies (in %) of people with CF with at least 1 hospitalization over the years

Structure of care

11d. Clinic visits

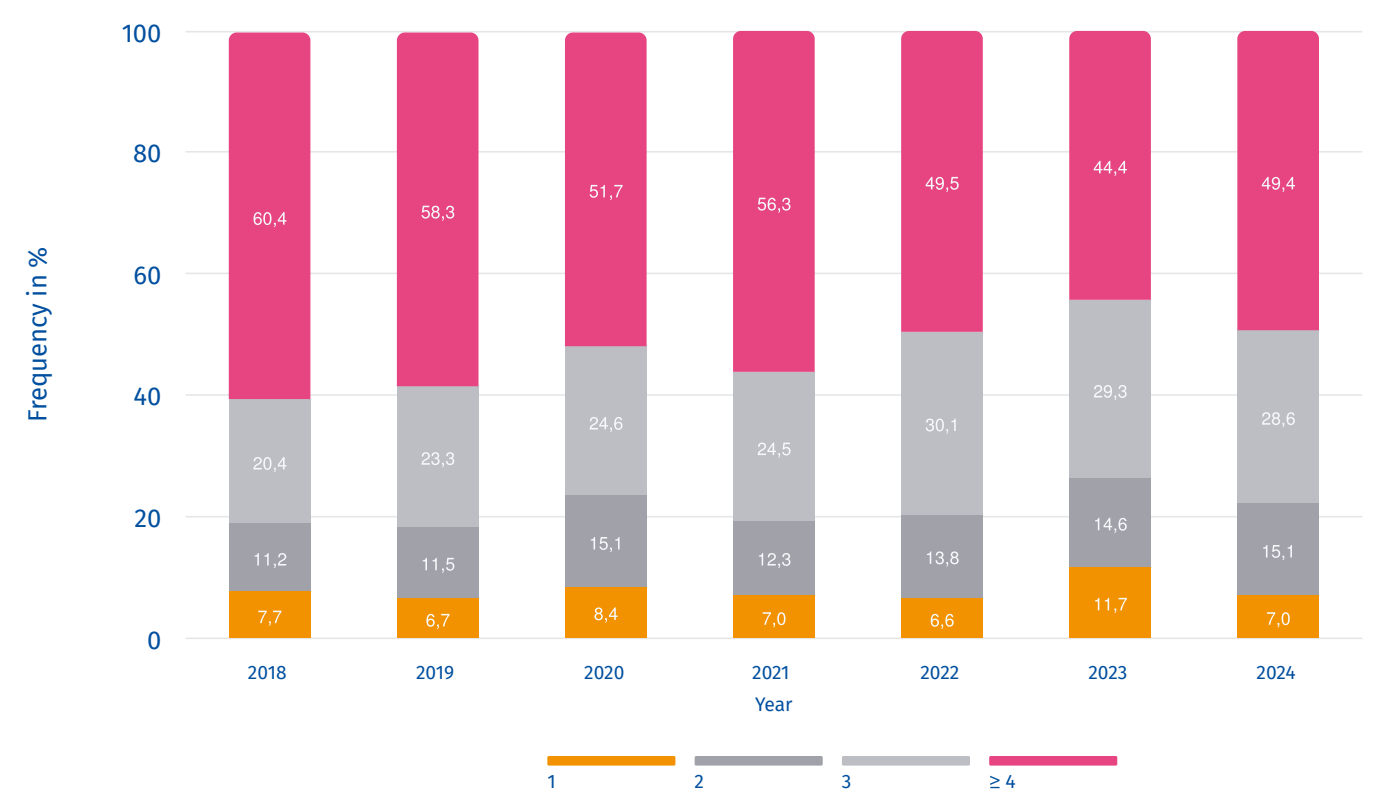


Fig. 55: Development of the number of documented clinic visits 2018 – 2024

YEAR	CLINIC VISITS IN THE CALENDAR YEAR			
	1	2	3	≥ 4
2024	7,0	15,1	28,6	49,4
2023	11,7	14,6	29,3	44,4
2022	6,6	13,8	30,1	49,5
2021	7,0	12,3	24,5	56,3
2020	8,4	15,1	24,6	51,7
2019	6,7	11,5	23,3	58,3
2018	7,7	11,2	20,4	60,4

Table 38: Development of the number of documented clinic visits (frequencies in %) 2018 – 2024

Structure of care

11e. Transplantations

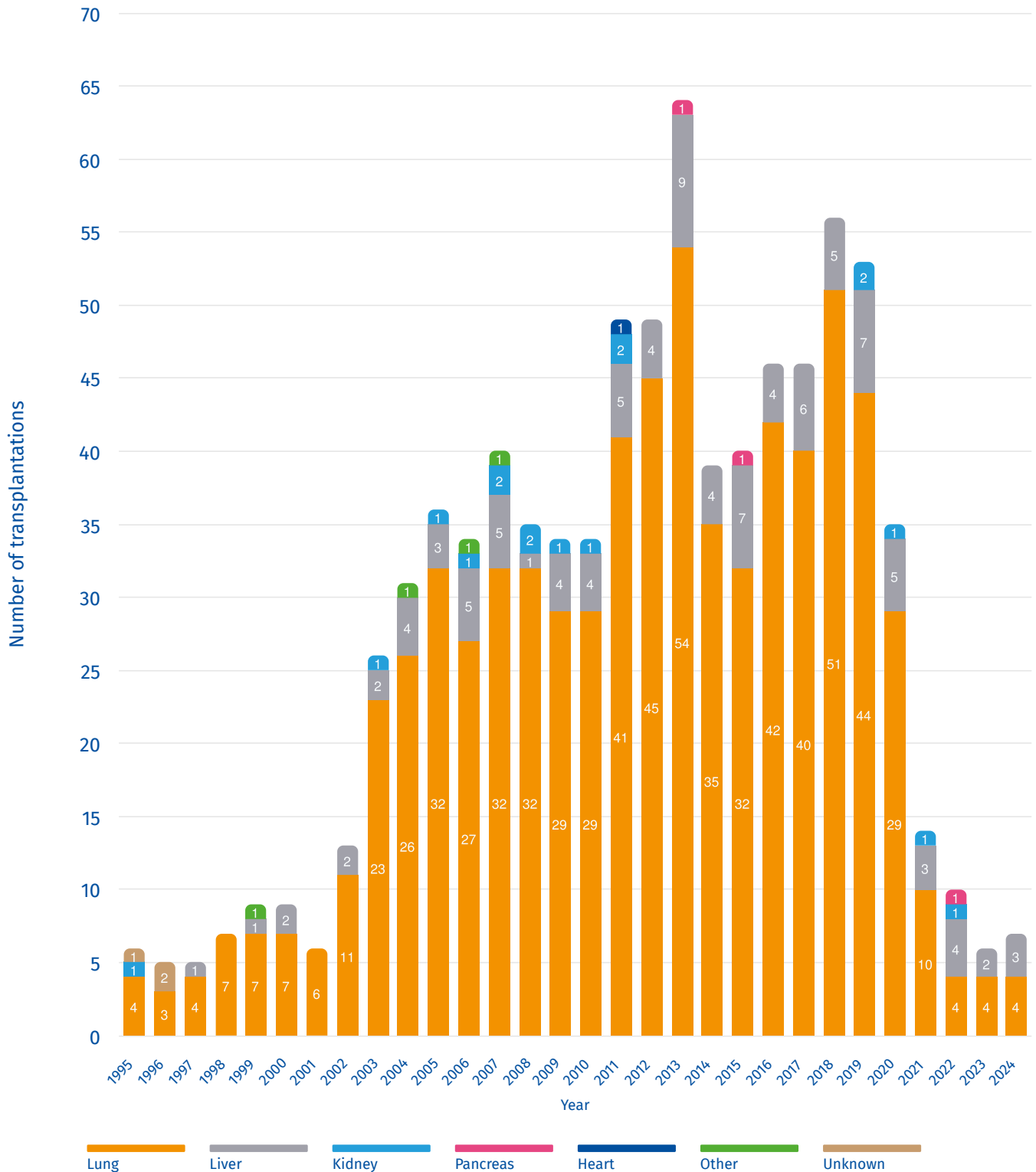


Fig. 56: Number of transplantations for the years 1995 – 2024

Structure of care

11e. Transplantations

YEAR	LUNG	LIVER	KIDNEY	PANCREAS	HEART	OTHER	UNKNOWN
2024	4	3	0	0	0	0	0
2023	4	2	0	0	0	0	0
2022	4	4	1	1	0	0	0
2021	10	3	1	0	0	0	0
2020	29	5	1	0	0	0	0
2019	44	7	2	0	0	0	0
2018	51	5	0	0	0	0	0
2017	40	6	0	0	0	0	0
2016	42	4	0	0	0	0	0
2015	32	7	0	1	0	0	0
2014	35	4	0	0	0	0	0
2013	54	9	0	1	0	0	0
2012	45	4	0	0	0	0	0
2011	41	5	2	0	1	0	0
2010	29	4	1	0	0	0	0
2009	29	4	1	0	0	0	0
2008	32	1	2	0	0	0	0
2007	32	5	2	0	0	1	0
2006	27	5	1	0	0	1	0
2005	32	3	1	0	0	0	0
2004	26	4	0	0	0	1	0
2003	23	2	1	0	0	0	0
2002	11	2	0	0	0	0	0
2001	6	0	0	0	0	0	0
2000	7	2	0	0	0	0	0
1999	7	1	0	0	0	1	0
1998	7	0	0	0	0	0	0
1997	4	1	0	0	0	0	0
1996	3	0	0	0	0	0	2
1995	4	0	1	0	0	0	1

Table 39: Number of transplantations for the years 1995 – 2024

Overview of Registry requests



You can access the registry requests at the following link:
www.muko.info/berichtsband

Participating CF facilities 2024

LOCATION	FACILITY	DEPARTMENT	NUMBER OF PATIENTS ¹
Aachen	Kinderarztpraxis Laurensberg	Fachärzte für Kinder- und Jugendmedizin	44
Aachen	Luisenhospital Aachen	Innere Medizin	100
Aue	HELIOS Klinikum Aue	Klinik für Kinder- und Jugendmedizin	10
Augsburg	KJF Klinik Josefinum Augsburg	Klinik für Kinder- und Jugendmedizin Sozialpädagogisches Zentrum (SPZ)	23
Augsburg	Universitätsklinikum Augsburg	Klinik für Kinder- und Jugendmedizin Kinderpneumologie und Allergologie	23
Augsburg	Universitätsklinikum Augsburg AöR		27
Baden-Baden	Klinikum Mittelbaden gGmbH	Klinik für Kinder- und Jugendmedizin Baden-Baden Balg	7
Berlin	Charité - Universitätsmedizin Berlin	Klinik für Pädiatrie m. S. Pneumologie und Immunologie - Christiane Herzog-Zentrum	314
Berlin-Lichtenberg	Sana Klinikum Lichtenberg	Klinik für Kinder- und Jugendmedizin	62
Bielefeld	Universitätsklinik für Kinder- und Jugendmedizin	Evangelisches Klinikum Bethel gGmbH	30
Bochum	UKRUB - Katholisches Klinikum Bochum	St. Josef Hospital - Klinik für Kinder- und Jugendmedizin - Christiane Herzog Zentrum	78
Brandenburg	Klinikum Westbrandenburg gGmbH	Standort Brandenburg Pädiatrische Pulmologie und Allergologie	38
Bremen	Eltern-Kind-Zentrum Prof. Hess	Klinik für Kinder- und Jugendmedizin Christiane Herzog-Zentrum	88
Chemnitz	Poliklinik Chemnitz gGmbH	Praxis für Kinder- und Jugendmedizin	34
Cottbus	Carl-Thiem-Klinikum Cottbus	Akademisches Lehrkrankenhaus der Charité Klinik für Kinder- und Jugendmedizin	29
Dresden	Universitätsklinikum Carl Gustav Carus	Haus 21 Universitäts-Mukoviszidose-Centrum (UMC)	212
Düsseldorf	UKD Universitätsklinikum Düsseldorf	Klinik für Allgemeine Pädiatrie, Neonatologie und Kinderkardiologie	27
Erfurt	Helios Klinikum Erfurt	Kinder- und Jugendmedizin	19
Erlangen	Universitätsklinikum Erlangen	Kinderklinik - Sozialpädiatrisches Zentrum	183
Essen	Universitätsklinikum Essen (AöR)	Klinik für Kinderheilkunde III Christiane Herzog Centrum Ruhr	103
Essen	Universitätsmedizin Essen	Ruhrlandklinik - Klinik für Pneumologie Christiane Herzog-Zentrum	366
Frankfurt	Universitätsmedizin Frankfurt a.M.	Klinik für Kinder- und Jugendmedizin Christiane Herzog CF-Zentrum	267
Frankfurt	Frankfurter Rotkreuz-Kliniken e.V.	Klinik für Pneumologie	22
Freiburg	Universitätsklinikum Freiburg	Kinder- und Jugendklinik (KJK)	87
Freiburg	Universitätsklinikum Freiburg	Klinik für Pneumologie	49
Gießen	Universitätsklinikum Gießen-Marburg GmbH	Zentrum für Kinderheilkunde und Jugendmed. Abteilung Allgemeine Pädiatrie und Neonatologie	106

¹ Patients may have been documented in multiple clinics

Participating CF facilities 2024

LOCATION	FACILITY	DEPARTMENT	NUMBER OF PATIENTS ¹
Gießen	Universitätsklinikum Gießen	Medizinische Klinik und Poliklinik II	100
Greifswald	Universitätsmedizin Greifswald	Klinik für Kinder- und Jugendmedizin	27
Halle	Universitätsklinikum Halle (Saale) UKH	Medizinische Fakultät der Klinik für Innere Medizin I	91
Hamburg	Kinder- und Jugendärztliche Gemeinschaftspraxis	Kinderärzte im Friesenweg CF Centrum Altona	138
Hamburg	Universitätsklinikum Eppendorf UKE	II. Medizinische Klinik und Poliklinik Sektion Pneumologie	104
Hamm	Johanniter Kliniken Hamm GmbH	Klinik für Kinder- und Jugendmedizin Pulmologie/Allergologie	11
Hannover	Medizinische Hochschule Hannover (MHH)	Klinik für Pädiatrische Pneumologie Christiane Herzog-Zentrum	182
Hannover	Medizinische Hochschule Hannover (MHH)	Klinik für Pneumologie	280
Heidelberg	Universitätsklinikum Heidelberg	Sektion Pädiatrische Pneumologie und Allergologie	128
Heidelberg	Universitätsklinik Heidelberg	Thoraxklinik Heidelberg gGmbH Pneumologie und Beatmungstherapie	276
Heilbronn	SLK-Kliniken Heilbronn GmbH	Klinik für Kinder- und Jugendmedizin Klinikum am Gesundbrunnen, Perinatalzentrum	14
Homburg	Universitätsklinikum des Saarlandes	Klinik für Allgemeine Pädiatrie und Neonatologie	64
Homburg	Universitätsklinikum des Saarlandes	Innere Medizin V - Pneumologie, Allergologie Beatmungs- und Umweltmedizin	63
Jena	Universitätsklinikum Jena	Klinik für Kinder- und Jugendmedizin	177
Karlsruhe	Städtisches Klinikum Karlsruhe gGmbH	Klinik für Kinder- und Jugendmedizin Pneumologie	29
Kassel	Klinikum Kassel	Pädiatrische Hämatologie und Onkologie, Psychosomatik und Systemerkrankungen	41
Kiel	Städtisches Krankenhaus Kiel	4. Medizinische Klinik Christiane Herzog Zentrum Nord	118
Kiel	Städtisches Krankenhaus Kiel GmbH	Kinderklinik und Jugendmedizin Christiane Herzog Zentrum Nord	49
Koblenz	Gemeinschaftsklinikum Mittelrhein gGmbH	Klinik für Kinder- und Jugendmedizin	43
Krefeld	Helios Klinikum Krefeld	Zentrum für Kinder- und Jugendmedizin	41
Köln	Universitätsklinikum Köln	Klinik für Kinder- und Jugendmedizin	254
Köln	Kliniken der Stadt Köln	Lungenklinik Merheim	83
Leipzig	Universitätsklinikum Leipzig	Klinik und Poliklinik für Kinder- und Jugendmedizin	66
Löwenstein	SLK-Kliniken Heilbronn GmbH	Fachklinik Löwenstein	39
Lübeck	Universitätsklinikum Schleswig Holstein (UKSH)	Campus Lübeck Klinik für Kinder- und Jugendmedizin	32
Magdeburg	Otto-von-Guericke-Universität Magdeburg	Klinik für Pneumologie	16

¹ Patients may have been documented in multiple clinics

Participating CF facilities 2024

LOCATION	FACILITY	DEPARTMENT	NUMBER OF PATIENTS ¹
Magdeburg	Otto-von-Guericke Universität Magdeburg	Kinderklinik	20
Mainz	Universitätsmedizin Mainz	Klinik für Kinder- und Jugendmedizin Pädiatrische Pneumologie und Allergologie	116
Marburg	Philipps Universität Marburg	Klinik für Kinder- und Jugendmedizin II Pädiatrische Pneumologie	22
Memmingen	Klinikum Memmingen	Klinik für Kinder- und Jugendmedizin	16
München	München Klinik Schwabing	Klinik für Kinder- und Jugendmedizin Allergologie, Pneumologie, Umweltmedizin	33
München	LMU Klinikum der Universität München	Kinderklinik und Kinderpoliklinik im Dr. von Haunerschen Kinderspital	299
München	Lungenheilkunde München Pasing		184
München	LMU Klinikum der Universität München	Campus Innenstadt Medizinische Klinik - Pneumologie	244
Münster	Universitätsklinikum Münster UKM	Klinik für Kinder- und Jugendmedizin Allgemeine Pädiatrie	64
Münster	Clemenshospital	Kinder- und Jugendmedizin	128
Neubrandenburg	Dietrich-Bonhoeffer-Klinikum	Klinik für Kinder- und Jugendmedizin	25
Oldenburg	Klinikum Oldenburg AöR	Klinik für Pädiatrische Pneumologie und Allergologie, Neonatologie und Intensivmedizin	108
Osnabrück	Christliches Kinderhospital Osnabrück	Zentrum für Kinder- und Jugendmedizin	70
Passau	Ordenskliniken München-Passau gGmbH	Standort Kinderklinik Dritter Orden Passau Kinderpneumologie	24
Potsdam	Klinikum Westbrandenburg gGmbH	Standort Potsdam Kinder- und Jugendklinik	274
Ravensburg	Oberschwabenklinik (OSK) gGmbH	St. Elisabethen-Klinikum	1
Regensburg	Klinik St. Hedwig	Kinder- und Jugendmedizin	69
Regensburg/Donaustauf	Klinik Donaustauf	Zentrum für Pneumologie	57
Rostock	Universitätsmedizin Rostock	Kinder- und Jugendklinik Pneumologie und Allergologie	27
Rüdersdorf bei Berlin	Immanuel Klinik Rüdersdorf	Kinder- und Jugendmedizin	5
Stuttgart	Klinikum Stuttgart - Olgahospital	Zentrum für chronische Lungenerkrankungen Christiane Herzog Transitionszentrum	157
Stuttgart	Robert Bosch Krankenhaus RBK	Pneumologie und Beatmungsmedizin	172
Trier	Klinikum Mutterhaus der Borromäerinnen	Kinder- und Jugendmedizin	19
Trier	Klinikum Mutterhaus der Borromäerinnen	Klinikum Mutterhaus Mitte, Innere Medizin 1	27

¹ Patients may have been documented in multiple clinics

Participating CF facilities 2024

LOCATION	FACILITY	DEPARTMENT	NUMBER OF PATIENTS ¹
Tübingen	Universitätsklinikum Tübingen	Klinik für Kinder- und Jugendmedizin	143
Ulm	Universitätsklinikum Ulm	Klinik für Kinder- und Jugendmedizin	123
Wangen	Waldburg-Zeil Kliniken	Fachkliniken Wangen Rehabilitationsklinik für Kinder und Jugendliche	13
Wangen	Waldburg Zeil Kliniken	Fachkliniken Wangen Klinik für Pneumologie	33
Wesel	Marien Hospital Wesel gGmbH	Klinik für Kinder- und Jugendmedizin	36
Worms	Klinikum Worms gGmbH	Klinik für Kinder- und Jugendmedizin	51

¹ Patients may have been documented in multiple clinics

All addresses can also be found at: www.muko.info/leben-mit-cf/adressen

Glossary

TERM	DEFINITION
ABPA Allergic bronchopulmonary aspergillosis	Development of an allergic reaction to <i>Aspergillus fumigatus</i> .
Anticholinergics	An anticholinergic has a relaxing effect on the smooth musculature and inhibits secretion.
Arthritis	A condition which causes pain and inflammation in the joints.
Arthropathy	A condition which causes pain in the joints.
Pancreas	An organ in the digestive system which produces insulin and digestive enzymes.
β2-sympathomimetics	Betasympathomimetics are pharmaceutical substances which stimulate the beta receptors of the sympathetic nervous system.
BMI (Body Mass Index)	A measure for evaluating a person's body weight in relation to their height.
<i>Burkholderia cepacia</i>	<i>Burkholderia cepacia</i> is a species of bacterium in the Burkholderia genus. Several of these bacteria are a potential threat to the health of people with Cystic Fibrosis.
CF (Cystic fibrosis)	Mucoviscidosis; Cystic Fibrosis
CFTR Regulator of the transmembrane conductance in Cystic Fibrosis	A protein on the cell surface which controls the sodium and water balance of a cell. The gene which causes Cystic Fibrosis is the blueprint for the CFTR protein. Every person has two copies of the gene for CFTR. Both CFTR genes must be affected by a mutation which causes CF, in order for someone to be born with Cystic Fibrosis.
Enzymes	Biological molecules present in the body (i.e. molecules occurring as metabolic products in the living cell) which support complex reactions such as the digestion of food.
FEV₁ one-second capacity	The one-second capacity is the largest-possible quantity of air which can be forced out of the lungs within 1 second. The FEV ₁ value is part of the pulmonary function and can be measured in a pulmonary function test.
FEV₁ % predicted	The FEV ₁ % is the percentage value of the average FEV ₁ which healthy people of the same age, gender and height can achieve. It is normally between 80 – 120%.
Gastroesophageal reflux disease	A chronic symptom of damage caused by gastric acid rising from the gastric mucosa.
Genotype	A characteristic part of the genetic structure of a cell, an organism or an individual.
<i>Haemophilus influenzae</i>	<i>Haemophilus influenzae</i> is a bacterium which can cause severe illness.
Haemoptysis	Coughing up blood.
Hepatobiliary disease	A liver or biliary disease.
Heterozygous	Everyone living with Cystic Fibrosis has two mutations of the gene for CFTR. One mutation is inherited from the mother and one from the father. If both mutations (or genotypes) are different, the person is heterozygous.
Homozygous	Everyone living with Cystic Fibrosis has two mutations of the gene for CFTR. One mutation is inherited from the mother and one from the father. If both mutations (or genotypes) are the same, the person is homozygous.
Interquartile range	The interquartile range is a measure of dispersion in descriptive statistics. If the sample is sorted by size, it indicates the width of the interval in which the mean 50% of the sample elements lie. It shows the difference between the upper and lower quartile: IQR = Q3 - Q1.

Glossary

TERM	DEFINITION
Confidence interval	An expectancy range to express how confident we are about our statistical estimates of a clinical measure. It shows a series of results which are likely to include the correct values for the population under study. A narrow confidence interval indicates a more accurate estimate. A wide confidence interval indicates greater uncertainty about the exact value of the measurement, often because only a small group of patients was studied.
Digestive tract / Gastrointestinaltract (GI)	The gastrointestinal tract (GI) is the main part of the digestive system which extends from the oesophagus to the anus. The GI is an organ system responsible for digesting food, absorbing nutrients and excreting faeces.
Median	The middle number when all numbers are arranged from the smallest to the largest number.
Median survival prognosis	A mathematical formula which can be used to predict the age which half the people born with CF today will reach. For example: 50 % of the people born today will reach the age of at least 47. The other 50% of these people will probably die before they reach this age.
Mean value	An average value calculated by adding up all the values and dividing by the number of values.
Average age at death	The average age at death is based on the people with CF who died in one year.
MRSA	Methicillin-resistant <i>Staphylococcus aureus</i> is a bacterial species which is resistant to a series of widely-used antibiotics.
Mutation	A mutation is an alteration to a gene. If both parents of a child are carriers of a mutation which causes Cystic Fibrosis, there is a 25% chance that the child will have CF. There are over 1,400 different mutations of the CFTR gene.
Hepatobiliary disease	Small sacciform growths caused by chronic inflammation of the nasal mucosa.
Newborn screening	Newborn screening is an examination of newborns which aims to detect congenital diseases at an early stage, e.g. Cystic Fibrosis.
Non-tuberculous mycobacteria (NTM)	A mycobacterium which does not cause tuberculosis but can still be the cause of respiratory tract infections. Several types are known.
Osteopenia	A disease which is less severe than osteoporosis and in which the mineral content of bones is reduced.
Osteoporosis	A condition in which the bones become brittle due to the loss of tissue.
Percentile	A percentile indicates where a value is relative to the rest of the data. If a value is higher than 90% of the rest of the data, it is referred to as the 90th percentile.
Pneumothorax	An accumulation of air in the cavity between the lung and the chest wall which can cause a pulmonary collapse on the affected side.
Prevalence	The total number of people with this disease in the last 12 months.
<i>Pseudomonas aeruginosa</i>	A strain of bacteria which rarely affects healthy people but can lead to a variety of infections in a weakened immune system. These infections often become chronic.

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