

# People living with Down syndrome in Europe: BIRTHS AND POPULATION

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**This fact sheet summarizes recently published estimates of the numbers of babies born and people living with Down syndrome in Europe.<sup>[1]</sup>**

## Births

- **How many babies are born with Down syndrome each year in Europe?** For the period 2011–2015, we estimate 8,031 annual live births of children with Down syndrome – a rate of around 1 in every 990 live births across Europe (10.1 per 10,000 live births; Figure 1).
- **What has happened to the birth rate over time in Europe?** Since the 1970s, the introduction and growth of prenatal screening and elective terminations has resulted in a live birth prevalence at around 10 per 10,000 live births, while the expected non-selective live birth prevalence has steadily increased since the early 1980s (Figure 1). Across Europe, the birth rate has declined by 11.0% over the past 30 years, though there are considerable differences between different regions and different countries (Figure 2). In the absence of prenatal screening and elective terminations, live birth rates across Europe today would be more than double current levels.

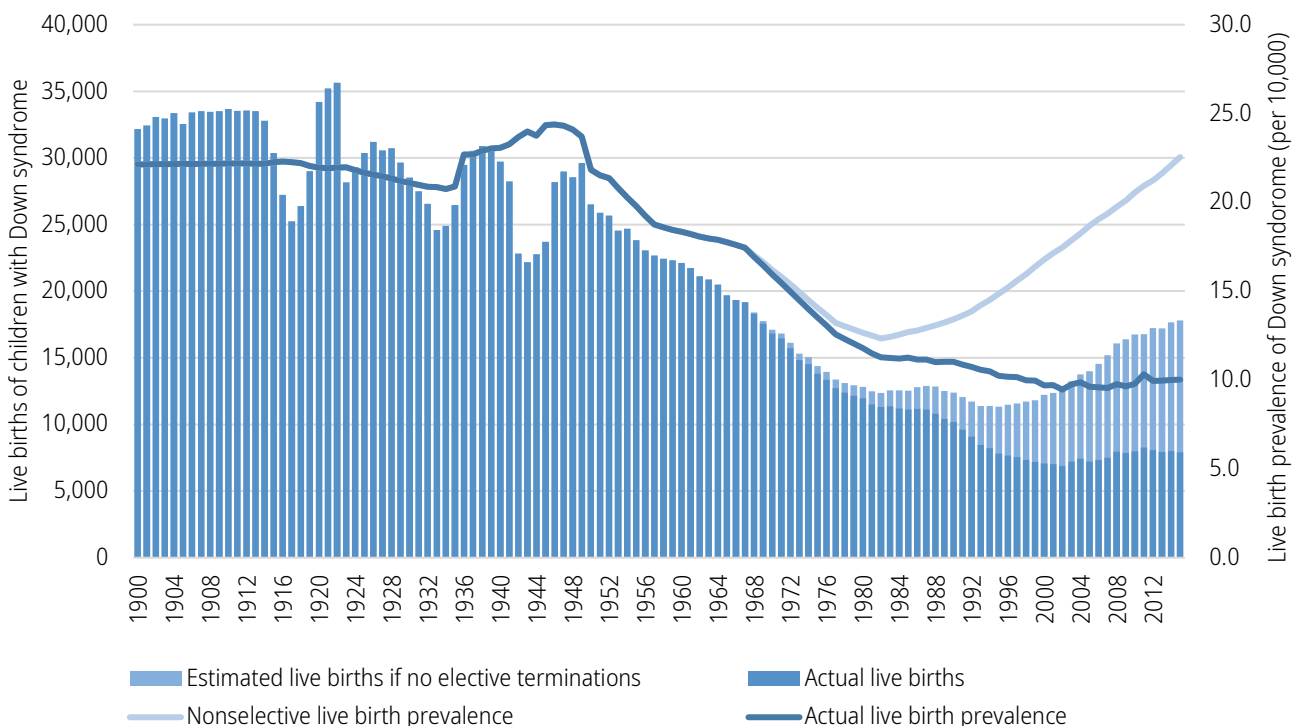
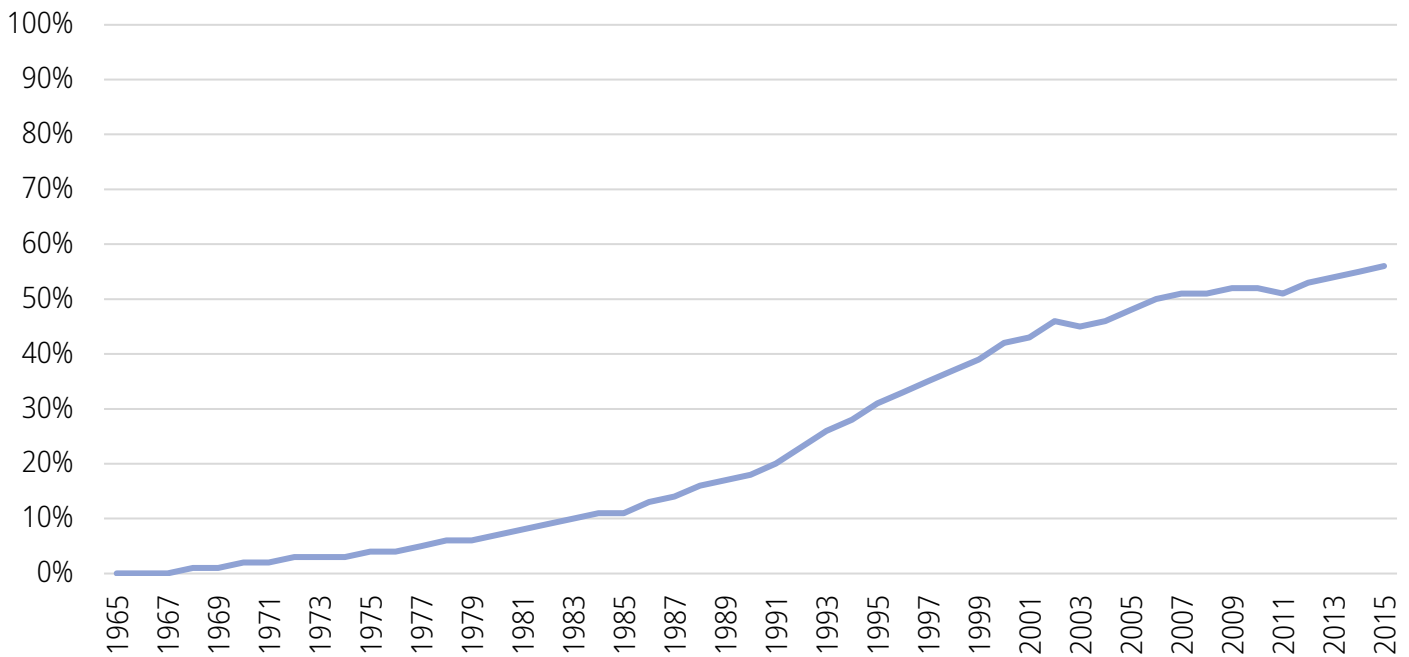


Figure 1. Births of babies with Down syndrome and live birth prevalence in Europe, 1900–2015.

Country	Nonselective live birth prevalence		Actual live birth prevalence		Change in nonselective live birth prevalence (%)	Change in actual live birth prevalence (%)
	1981-1985	2011-2015	1981-1985	2011-2015		
Ireland *	19.46	30.07	19.46	27.80	54.5%	42.8%
Malta *	17.40	20.12	17.40	20.12	15.6%	15.6%
Hungary	10.75	23.14	7.80	8.97	115.2%	15.1%
Germany	12.07	24.42	10.69	12.21	102.3%	14.2%
Russian Federation	11.44	16.94	10.20	11.54	48.2%	13.0%
Ukraine	11.27	15.62	11.27	12.59	38.7%	11.7%
Croatia	11.30	20.24	11.30	12.29	79.0%	8.8%
Sweden	15.05	23.95	13.19	14.29	59.1%	8.4%
United Kingdom	12.95	22.55	9.56	10.32	74.1%	8.0%
Norway	13.23	22.48	11.37	12.13	70.0%	6.7%
Serbia	13.22	18.12	13.22	13.89	37.1%	5.1%
Netherlands	12.79	22.51	11.47	12.02	76.0%	4.7%
Republic of Moldova	12.24	13.42	12.24	12.29	9.6%	0.3%
Romania	11.68	17.02	11.68	11.40	45.8%	-2.4%
Luxembourg	12.74	27.03	10.38	9.68	112.2%	-6.8%
North Macedonia	11.42	16.01	10.46	9.64	40.2%	-7.8%
Switzerland	13.61	26.56	10.36	9.44	95.1%	-8.9%
Austria	12.67	23.01	9.88	8.89	81.6%	-10.0%
Slovakia	10.24	18.95	8.85	7.95	85.0%	-10.1%
Belgium	11.74	23.27	7.97	7.08	98.2%	-11.2%
Finland	15.32	22.43	12.39	10.30	46.3%	-16.9%
Greece	12.65	27.66	12.16	9.44	118.7%	-22.4%
Belarus	11.25	15.31	11.25	8.23	36.0%	-26.8%
Bosnia and Herzegovina	12.11	16.89	12.11	8.64	39.6%	-28.6%
Montenegro	13.25	18.89	13.25	9.44	42.5%	-28.8%
Italy	14.77	32.99	13.56	9.62	123.4%	-29.0%
France	12.66	22.21	10.34	7.19	75.4%	-30.5%
Latvia	12.56	21.84	12.56	8.25	73.8%	-34.3%
Lithuania	13.83	17.97	13.83	8.92	29.9%	-35.5%
Poland	12.56	18.35	12.56	7.86	46.1%	-37.4%
Czech Republic	9.99	21.15	7.97	4.83	111.7%	-39.4%
Iceland	13.32	21.96	11.42	6.86	64.9%	-39.9%
Albania	15.93	13.56	15.93	9.02	-14.8%	-43.3%
Denmark	12.57	23.31	8.96	4.88	85.4%	-45.5%
Bulgaria	9.53	17.30	9.29	4.54	81.5%	-51.1%
Slovenia	11.34	20.60	11.20	4.87	81.6%	-56.5%
Estonia	12.19	21.37	12.19	5.16	75.2%	-57.7%
Spain	16.35	33.04	16.14	5.49	102.1%	-66.0%
Portugal	15.36	25.80	14.87	5.05	67.9%	-66.1%
<b>Europe</b>	<b>12.50</b>	<b>21.69</b>	<b>11.30</b>	<b>10.05</b>	<b>73.5%</b>	<b>-11.0%</b>
United States	11.58	19.22	9.94	12.88	66.0%	29.6%

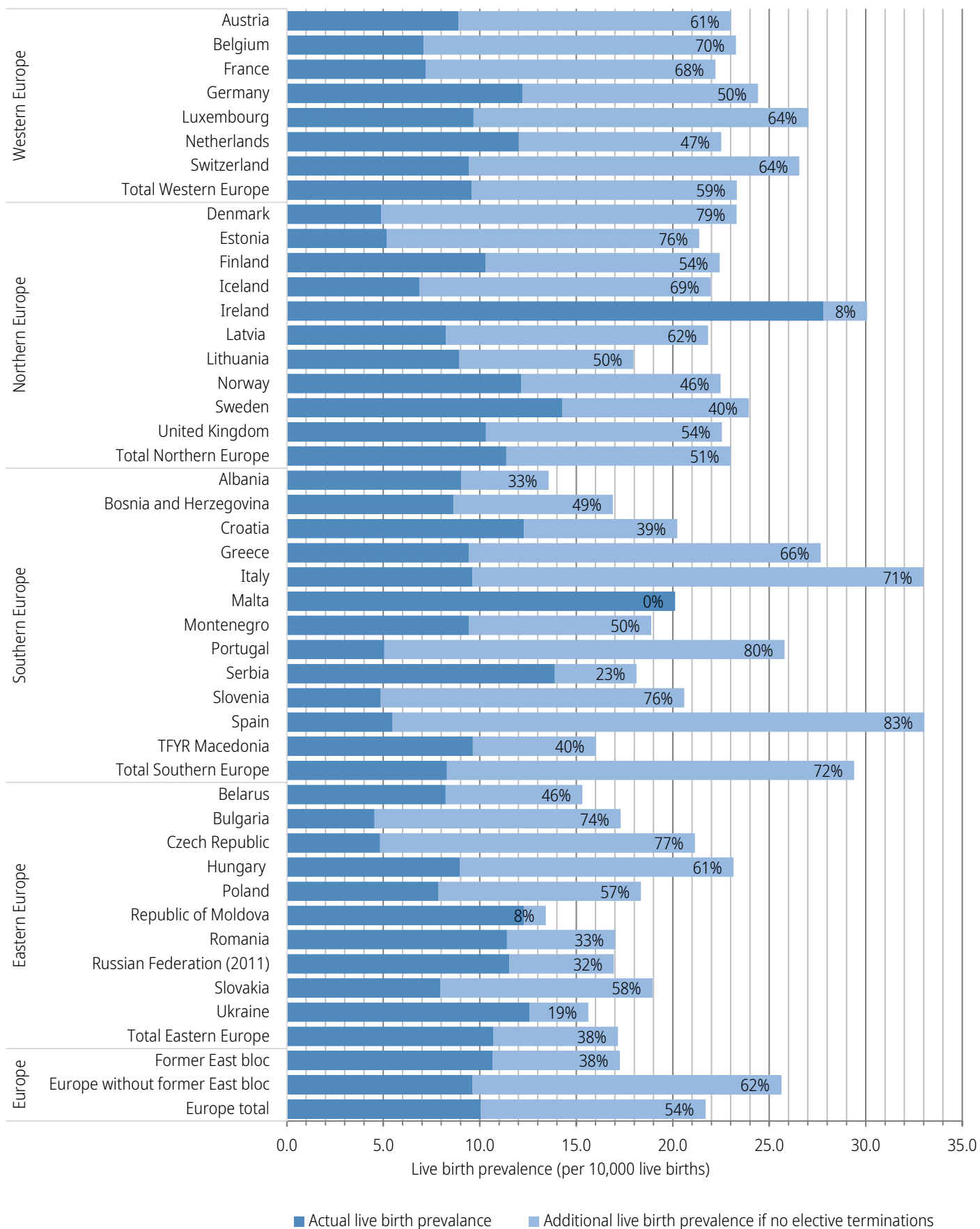
**Figure 2. Changes in the nonselective and live birth prevalence of Down syndrome in European countries, between 1981–1985 and 2011–2015.** \* Termination of pregnancies were not permitted by law in Ireland and Malta during these periods. (US comparison based on previously reported modelling,<sup>[2-4]</sup> updated with recent data.)

- **Are more pregnancies with Down syndrome being terminated in Europe than in the past?** In the few decades since prenatal screening was introduced, more pregnancies with Down syndrome have been diagnosed prenatally and terminated. However, not all children born with Down syndrome are diagnosed prenatally, and many expectant parents do not choose screening. Therefore, reductions in live birth rates are influenced by the number of people choosing prenatal testing, the accuracy of the screening tests, and parents' decisions given a prenatal diagnosis. The percentage of live births of babies with Down syndrome reduced as a result of screening and terminations has steadily risen in Europe over the past 40 years to over 50% today (Figure 3). Put another way, this means that in recent years there were 50% fewer babies with Down syndrome than could have been born in Europe, absent elective terminations.



**Figure 3. The percentage of live births of babies with Down syndrome reduced as a result of screening and elective terminations in Europe, 1965–2015.**

- **How are newer non-invasive screening technologies influencing birth rates?** Noninvasive prenatal screening (NIPS) has only recently been implemented in certain European countries. As data from these recent years are not yet available, our modeling does not yet provide an assessment of the impact of NIPS within Europe.
- **Are similar numbers of babies with Down syndrome born in all regions and all countries throughout Europe?** Differences in maternal ages, different laws, healthcare provisions, and cultural attitudes lead to differences in birth rates between different countries and regions. Among the four geographic European regions, between 2011 and 2015, live birth prevalence was lowest (8.3 per 10,000) in Southern Europe and highest in Northern Europe (11.4 per 10,000) with a reduction rate of 72% in Southern Europe and a reduction rate of 51% in Northern Europe (Figure 4). Within each region, there are substantial differences between individual countries (Figure 4).<sup>[a]</sup>



**Figure 4. Live birth prevalence of people with Down syndrome per 10,000 live births in Europe, 2011–2015, and the effect of elective terminations.** Percentages represent the reduction of Down syndrome prevalence as a consequence of selective terminations.

# Population

- **How many people with Down syndrome are living in the Europe today?** On basis of our modelling,<sup>[a]</sup> we estimate that 417,000 people with Down syndrome were living in Europe as of 2015 (Figure 5).

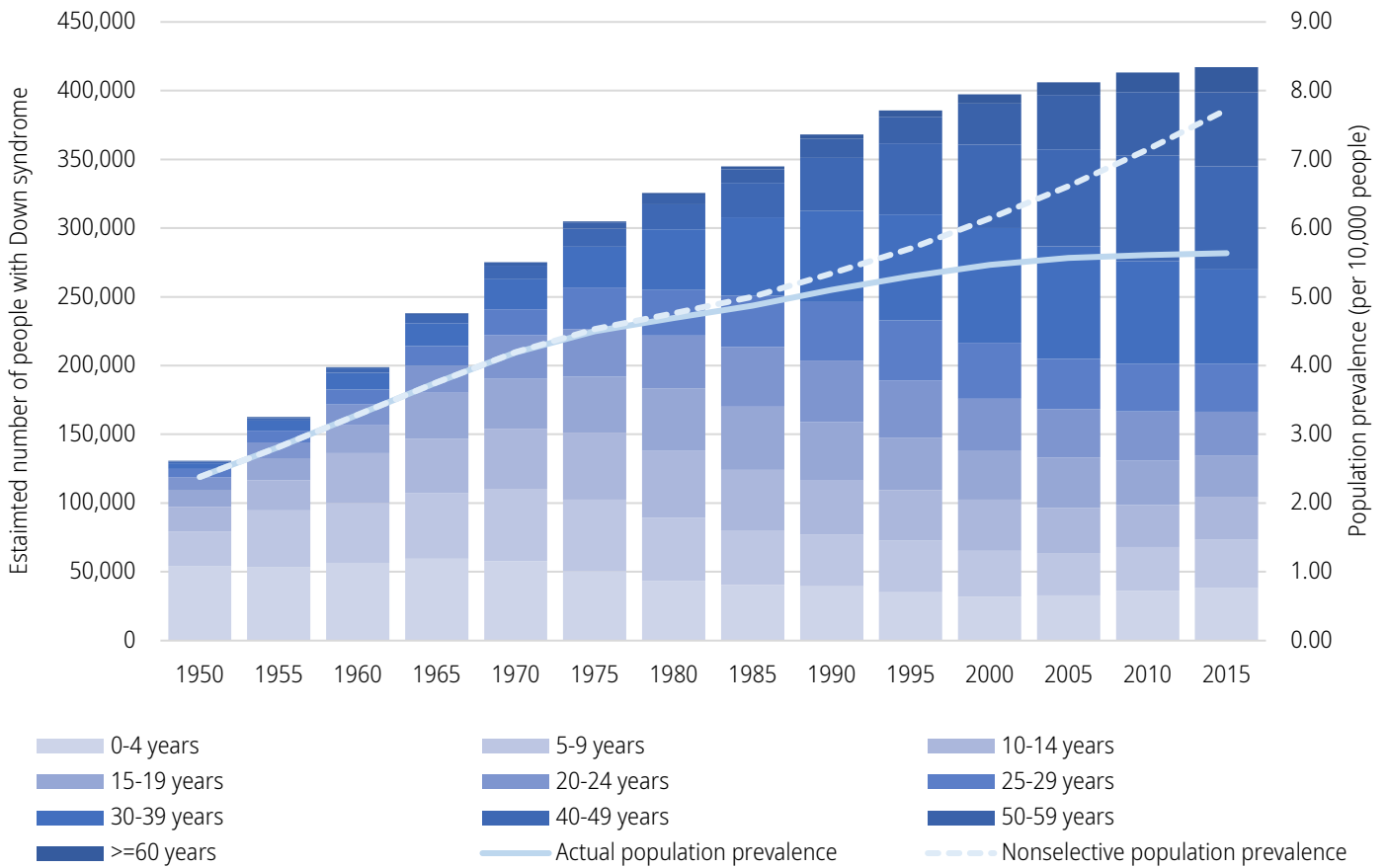
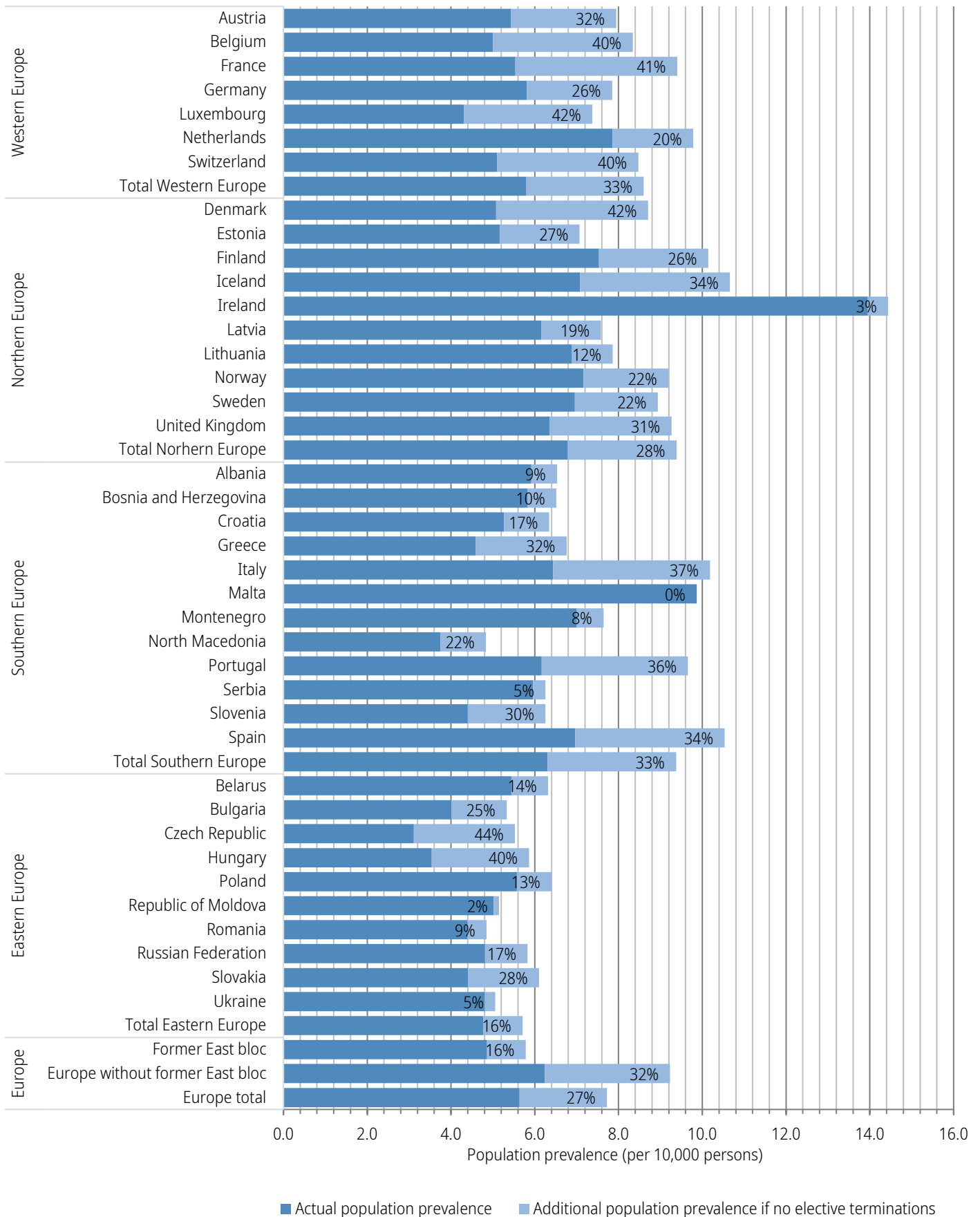


Figure 5. The number of people living with Down syndrome in Europe, 1950–2015.

- **What proportion of the European population are people with Down syndrome?** The population prevalence of Down syndrome in Europe, as of 2015, is estimated at 5.6 per 10,000 inhabitants (or 1 in 1,786; Figure 6).
- **How has life expectancy changed for people with Down syndrome?** For European countries that were not formerly part of the East bloc, there has been a steep rise in median life expectancy between 1950 and 1970 from around 3 years in 1950 to around 53 years of age in 1970, followed by a gradual rise to 58 years of age, in more recent years. Our model suggests that for former East bloc countries, the rise in median life expectancy occurred later, for some countries only as of 1995. More recently, according to our modeling, the median life expectancy in these countries is also approaching 58 years of age.



**Figure 6. The prevalence of people living with Down syndrome in Europe, 2015.** Percentages reflect the reduction in the population prevalence of Down syndrome because of selective terminations.

# Notes

- a. We have assumed that a lower 1-year survival in the general population will be indicative for a less well-developed medical care system, which will concomitantly impact the survival of children with DS. For the different European countries, we constructed country-specific survival curves by year of birth for people with DS on the basis of their historical and current 1-year mortality rates in the general population. We compared the model projections with population counts of people with DS (available for 8 countries), and with data on the distribution of age at death of people with DS from national statistics (available for most countries). For former West bloc countries, the projections matched the empirical data. However, the model had a very poor fit with empirical data from former East bloc countries. We developed an alternative model of survival for the former East bloc countries, with a less favorable survival of people with DS up to 2000. Projections of this alternative model had a far better match with the empirical data. Further details are available in our paper and supplementary materials.<sup>[1]</sup>
- b. Data on live births of children with Down syndrome were based on EUROCAT Registry of Congenital Anomalies and published results of estimates for some countries. It is important to realize that for many countries there is some uncertainty in the estimates of actual LB prevalence due to incompleteness of data. Sources and uncertainties are detailed in the supplementary information available with our paper.<sup>[1]</sup>

# References

1. de Graaf, G., Buckley, F. & Skotko, B.G. (2020). Estimation of the number of people with Down syndrome in Europe. *European Journal of Human Genetics*. doi:10.1038/s41431-020-00748-y Available: <https://rdcu.be/b9w27> Supplementary information available: <https://www.readcube.com/articles/supplement?doi=10.1038%2Fs41431-020-00748-y&index=0>
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3. de Graaf G., Buckley F., Skotko B. G. (2017). Estimation of the number of people with Down syndrome in the United States. *Genetics in Medicine*, 19, 439-447. doi:10.1038/gim.2016.127
4. de Graaf G., Buckley F., Dever J., Skotko B. G. (2017). Estimation of live birth and population prevalence of Down syndrome in nine U.S. states. *Genetics in Medicine*, advance online publication. doi:10.1002/ajmg.a.38402

# US factsheet

A factsheet detailing our latest estimates of the births and population of people with Down syndrome in the USA is also available:

<https://go.downsyndromepopulation.org/usa-factsheet>

Region/country	Number
<b>Western Europe</b>	<b>111,304</b>
Austria	4,716
Belgium	5,646
France	35,684
Germany	47,465
Luxembourg	243
Netherlands	13,309
Switzerland	4,241
<b>Northern Europe</b>	<b>69,760</b>
Denmark	2,887
Estonia	679
Finland	4,130
Iceland	234
Ireland	6,557
Latvia	1,226
Lithuania	2,020
Norway	3,725
Sweden	6,792
United Kingdom	41,511
<b>Southern Europe</b>	<b>96,075</b>
Albania	1,729
Bosnia and Herzegovina	2,063
Croatia	2,232
Greece	5,146
Italy	38,330
Malta	423
Montenegro	440
North Macedonia	780
Portugal	6,421
Serbia + Kosovo	5,275
Slovenia	913
Spain	32,323
<b>Eastern Europe</b>	<b>139,997</b>
Belarus	5,161
Bulgaria	2,879
Czech Republic	3,299
Hungary	3,463
Poland	21,328
Republic of Moldova	2,041
Romania	8,736
Russian Federation	69,220
Slovakia	2,396
Ukraine	21,474

**Table 1. The estimated number of people living with Down syndrome in European countries in 2015**