

Birth and population prevalence for Down syndrome in European countries*

* Corrected September 24th 2018, as there were errors in the estimations of LB-prevalence for Serbia and for the Baltic states

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BACKGROUND How many children with Down syndrome are born in different European countries? How many people with Down syndrome live in these countries, and what are their ages? To plan support, this information can be useful.

METHODS A demographic model was developed to estimate numbers of people with Down syndrome by age in the population. The model uses (1) an estimation of number of potential live births of children with Down syndrome on basis of maternal ages in population, (2) counts of actual births of children with Down syndrome, and (3) a model for historical survival in people with Down syndrome. Previously, this model has been used and validated for the Netherlands, Ireland, the UK and the US. For former East bloc countries, we compared the model predictions with empirical counts in four of these countries, and we constructed an alternative model for survival on basis of this comparison.

Data on maternal age distribution were derived from multiple sources, i.e., the 2017 Revision of the World Population Prospects of the Population Division of the United Nations, Demographic Yearbooks of the United Nations Statistics Division, and data from national statistical offices. Data before 1950 were either derived from national statistical offices or from the Demographic Yearbooks of the UN, or for countries without data, extrapolated on basis of age-specific fertility rates in 1950 to 1960 and the female age distribution in 1950, derived from the World Population Prospects.

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. For countries lacking information, we have assumed that net reduction percentage in live births of children with Down syndrome as a result of elective terminations is comparable with that in countries geographically and culturally akin, i.e., reduction due to elective terminations in Luxembourg was modelled in line with France, Germany and Belgium; Iceland like Denmark; Latvia and Lithuania like Estonia; Belarus like Russia; Bosnia and Herzegovina, Greece, Montenegro, Serbia; TFYR Macedonia like Slovenia.

De Graaf et al. (2017; doi: 10.1038/gim.2016.127) constructed survival curves for people with Down syndrome for different years of birth in Western countries. They adapted these curves for different ethnic groups in the U.S. on basis of 1-year ethnicity-specific mortality rates in the general population. For the European countries, we followed this method in constructing country-specific survival curves for children with DS on the basis of their historical and current 1-year mortality rates in the general population. Data on 1-year survival in general population were derived from the 2017 Revision of the World Population Prospects for the period after 1950, and from the Gapminder Foundation for earlier years. For countries lacking information on mortality before 1950, rates were extrapolated.

We compared modeled estimates of number of people with Down syndrome alive, and on distribution of age at death for 2010 and 2015, with empirical information, if available.

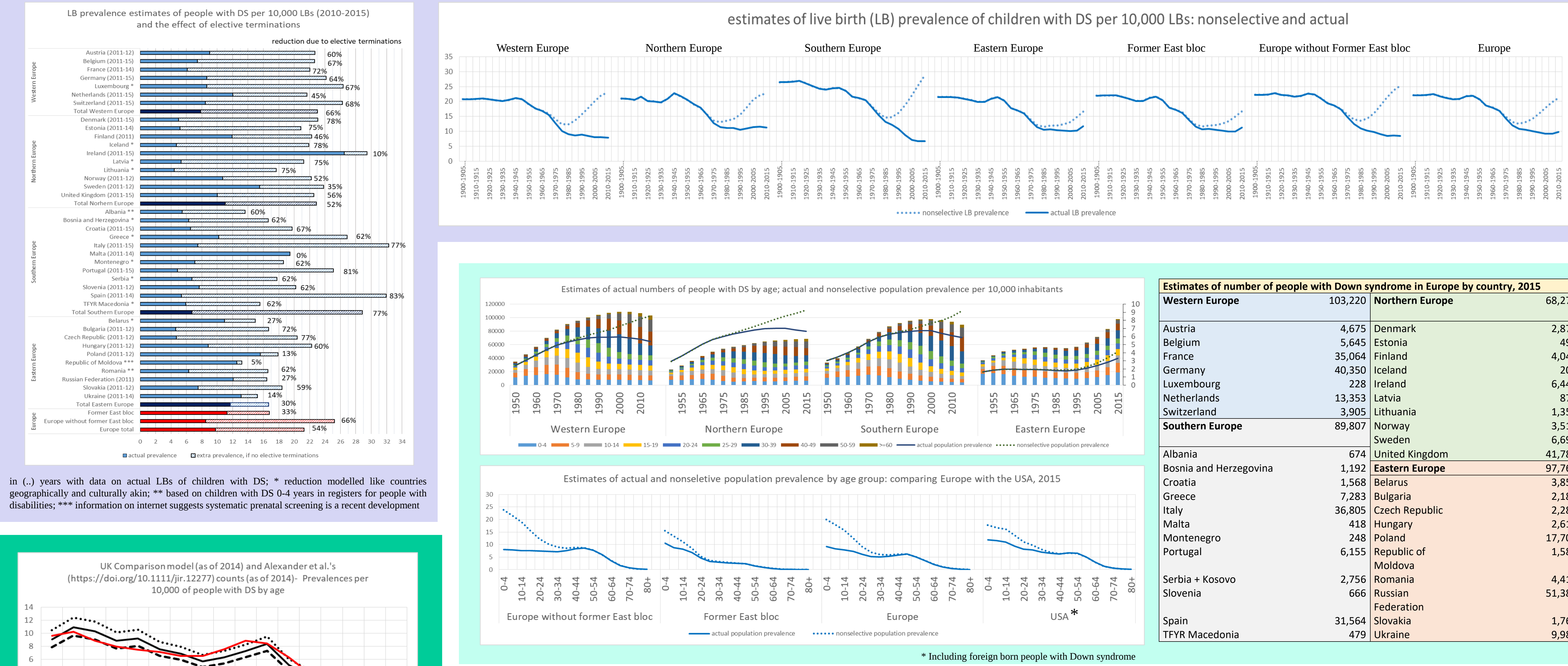
RESULTS

The model appears to work well for non-former-East-bloc-countries. The model predictions are in line with historical counts of numbers of people with Down syndrome by age in the UK, Ireland, Spain and Denmark. For non-former-East-bloc-countries (with the exception of Greece), the distribution of age at death for people with Down syndrome in 2010 and 2015, as predicted by the model, matches this distribution as reported for people with Down syndrome by the Global Health Data Exchange of the Institute for Health Metrics and Evaluation (IHME) at the University of Washington.

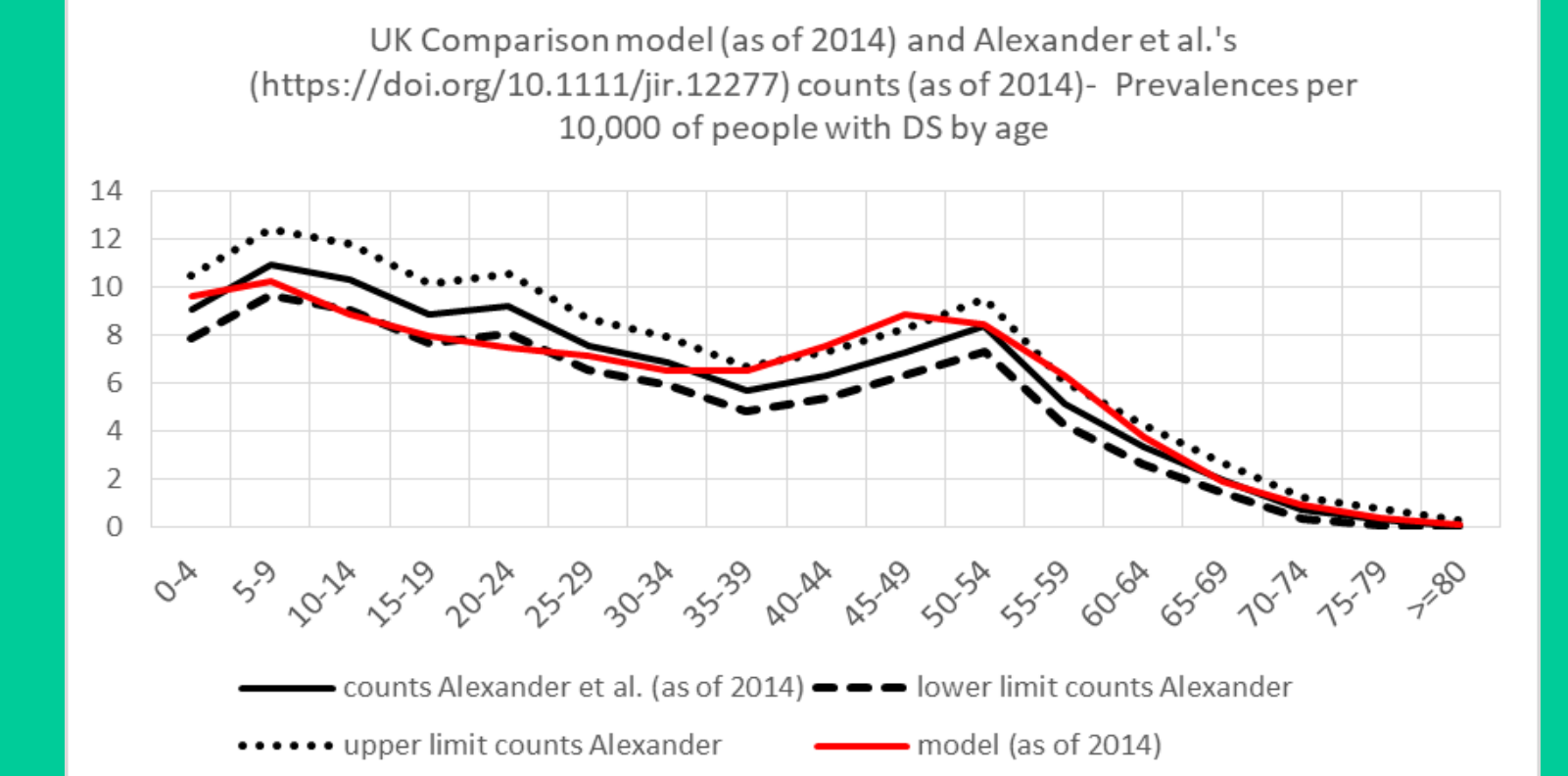
Missing data on the historical survival of people with Down syndrome in former East bloc countries complicates the estimations of numbers alive in these countries. On basis of a comparison between model predictions (based on survival of people with Down syndrome in Western countries under adaptation for differences in general 1-year mortality rates) and counts in four Eastern European countries, a tentative alternative survival model for former East bloc countries was developed. For these countries, a far less favorable survival must be assumed, especially before 1990. The distribution of age at death as predicted by this alternative model has a better match with this distribution as reported by the Global Health Data Exchange.

For Europe, in the period 2011-2015, we estimate 7,800 annual live births of children with Down syndrome, which corresponds with a live birth prevalence of 9.8 per 10,000 live births. Without elective terminations, live birth prevalence would have been around 21.3 per 10,000 live births, or 17,000 births annually. Reduction of live birth prevalence by elective terminations during this period was on average 54%, but varies between 0% in Malta to 83% in Spain. European Down syndrome population prevalence as of 2015 is estimated at 4.9 per 10,000. **We estimate there to be 359,000 people with Down syndrome living in Europe**, of whom 35% are under the age of 20 and 35% above 40 years old. Without elective terminations, nonselective population prevalence would have been 7.1 per 10,000, or 521,000 people (reduction 31%). By comparison, we estimate 5,000 annual live births of children with Down syndrome in the U.S. in 2011-12 (12.7 per 10,000). This would have been 7,500 (18.8 per 10,000) without elective terminations (33% reduction due to elective terminations). As of 2015, estimated on basis of the method of De Graaf et al. (2017), around 215,000 people with Down syndrome (including 5,800 foreign born) are living in the U.S. (6,7 per 10,000). This would have been 271,000 (8,5 per 10,000) (including 5,800 foreign born) without elective terminations (21% reduction due to elective terminations).

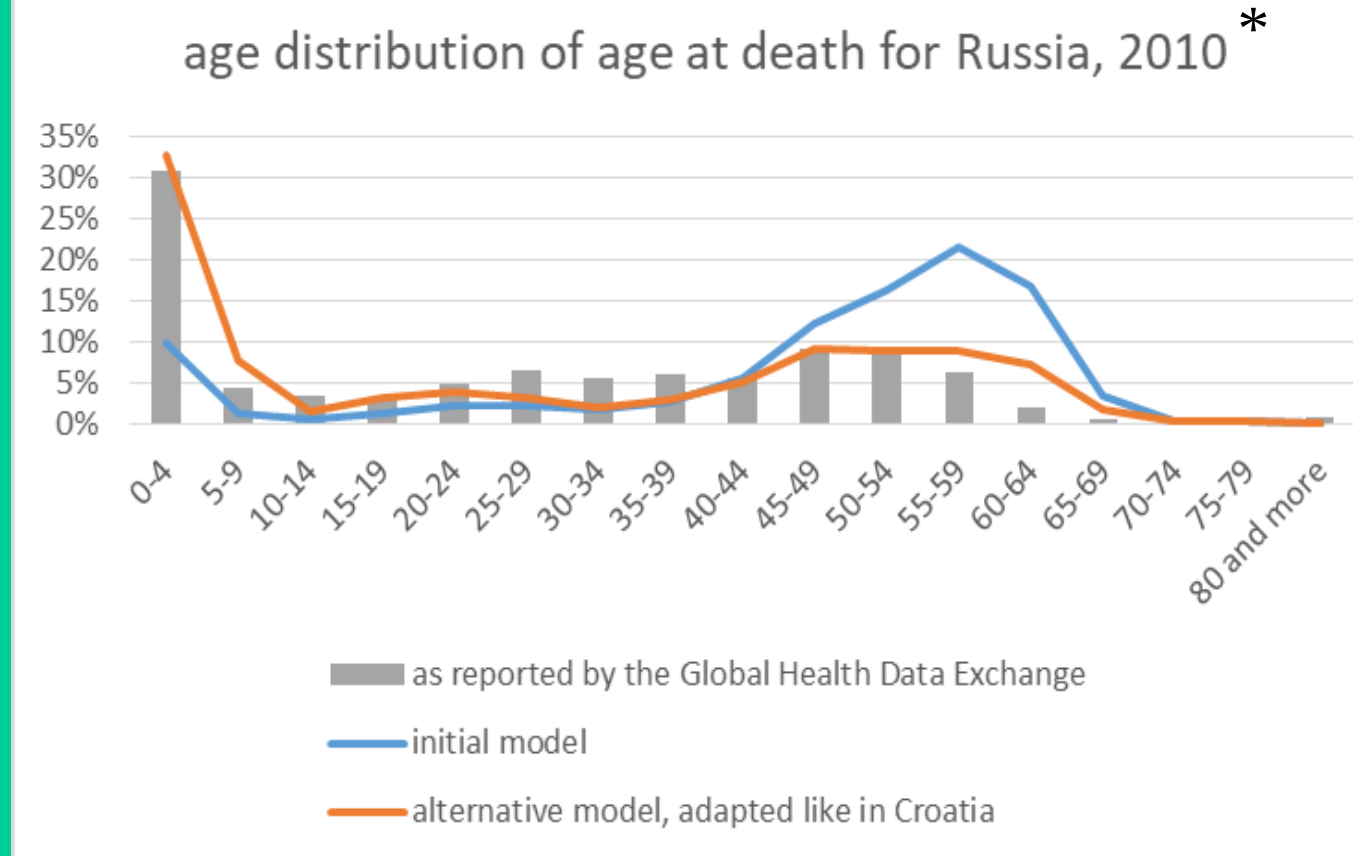
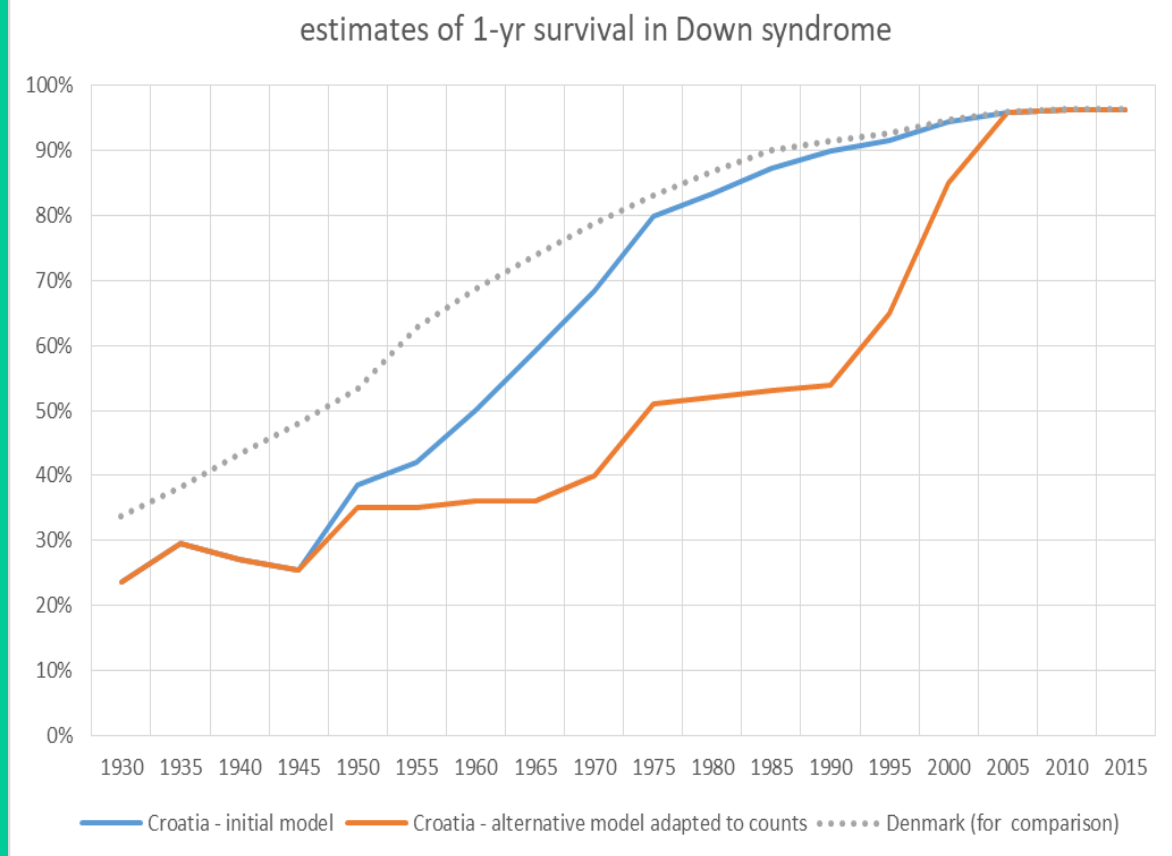
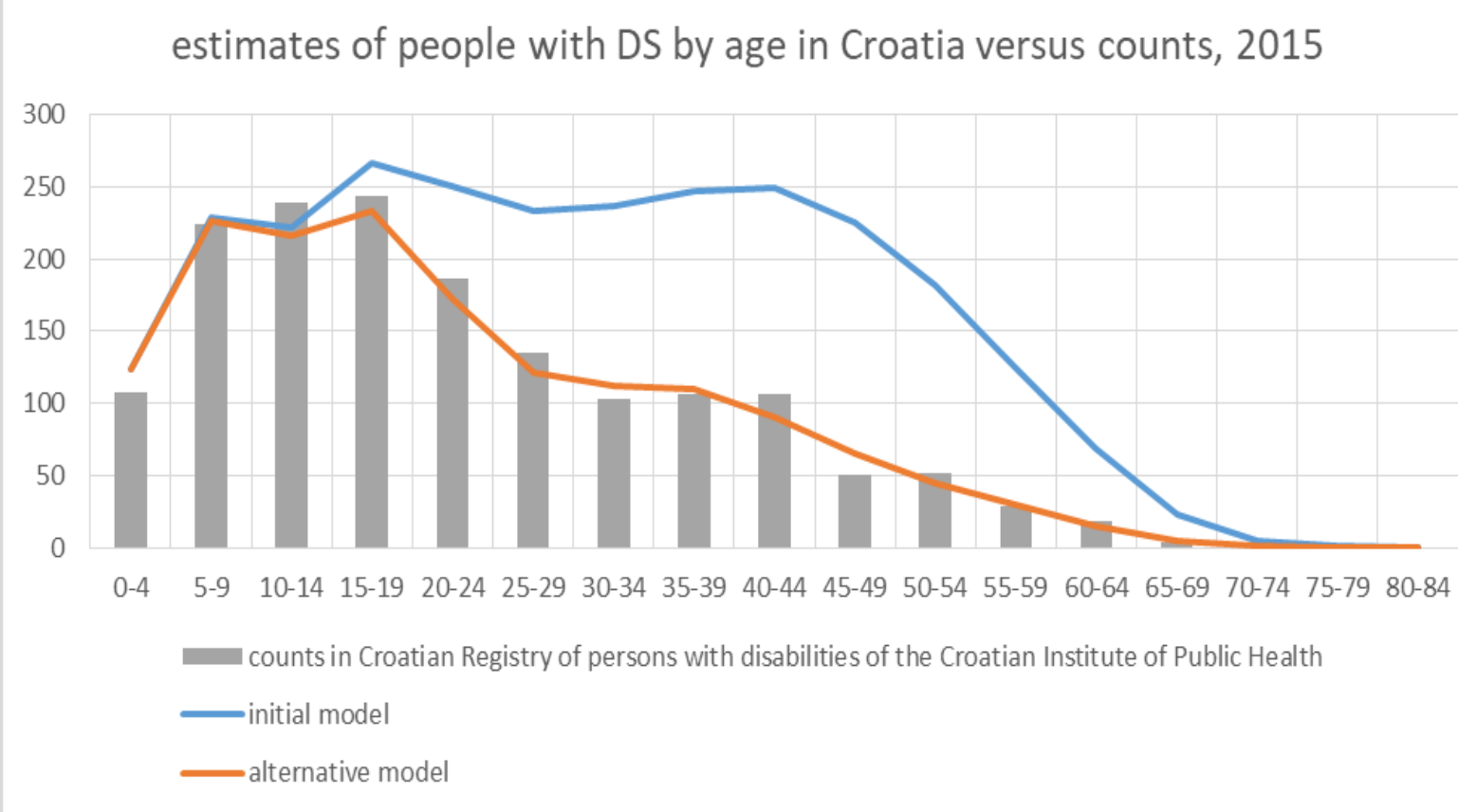
CONCLUSION The demographic model can be used for estimating the number of people with Down syndrome alive by age group in non-former-East-bloc countries. For former East bloc countries, the model had to be adapted. To further validate the model, empirical counts of people with Down syndrome by age group in these countries would be helpful.



in (.) years with data on actual LBs of children with DS; * reduction modelled like countries geographically and culturally akin; ** based on children with DS 0-4 years in registers for people with disabilities; *** information on internet suggests systematic prenatal screening is a recent development



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* We present the results for Russia as an example of how we adapted the model for the former East bloc