

Down Syndrome in the Netherlands, England/Wales and Ireland Past and Prospects; a demographic model for birth and population prevalence

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INTRODUCTION The Netherlands are lacking reliable empirical data in relation to the development of birth and population prevalence of Down syndrome. For the UK and in Ireland there are more historical empirical data available.

AIM A theory based model is developed for predicting Down syndrome prevalence in The Netherlands from the 1950's onwards. It is likewise applied to Ireland and the UK for the purpose of validation. Furthermore, a prediction to 2050 is constructed.

Figure 1

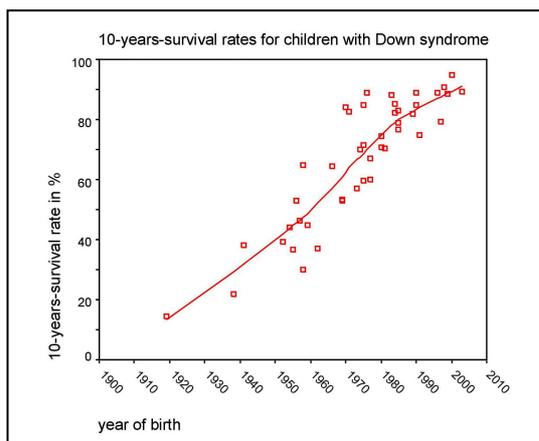
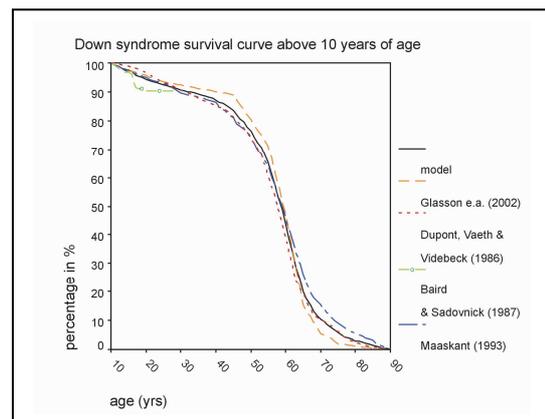


Figure 2



METHODS Maternal age births data in the general population (from the national statistical offices CBS, CSO and ONS), maternal age related risk of Down syndrome (Morris et al, 2002), data on selective terminations of Down syndrome pregnancies (from the NDSCR and WPDT) and mortality rates were obtained to create this model. Results from 35 studies were used to estimate 10-years-survival rates for the respective years of birth (see figure 1). For each study the survival rate was plotted against the year of birth and a regression line was drawn with the non-parametric SPSS LOESS function. The same procedure was used for estimating 1- and 5-years-survival rates. Survival rates for intermediary ages were extrapolated. For modeling survival rates above 10-years of age, data were used from 4 studies (figure 2). In order to apply this model for future predictions, it was necessary to make some additional assumptions. Most important are the assumptions of an unchanged high maternal age at birth and only a slight increase in reduction percentages due to selective abortion in coming years.

Figure 3

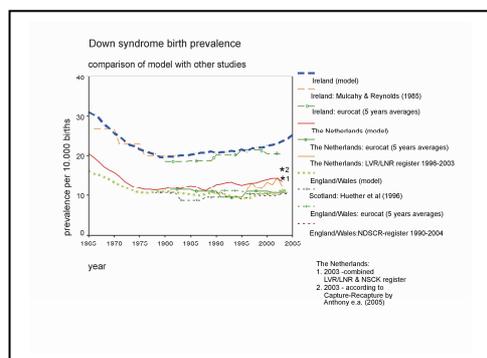
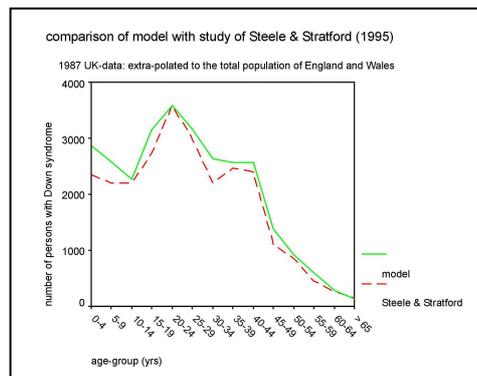


Figure 4



RESULTS For The Netherlands nowadays birth prevalence is estimated at 14 per 10.000 with around 275 total annual births. The impact of selective abortion is lower than in the UK. Present Dutch Down syndrome population prevalence is estimated, according to this theory based model, at 7,7 per 10.000 and the grand total at 12.600 individuals, of whom approximately 4.600 are under the age of 20 and 4.500 above 40 years old.

Validity of this theory based model was examined by comparison with relevant available empirical data from the three countries. The model shows a good fit with historical empirical research, notably eight birth prevalence studies (figure 3) and four UK (Penrose, 1949; Midwinter, 1972; Stratford & Steele, 1985; Steele & Stratford, 1995) and two Irish population prevalence studies (in Mulcahy & Reynolds (1985), in regard to total population prevalence rates and age distribution as well. As an illustration in figure 4 a comparison is shown between the results from the theory based model and the study by Steele & Stratford (1995). In 1987 these researchers in 30 different Social Service and Health Authority registers across the UK identified about 3.700 persons with Down syndrome in a total population of approximately 7 million.

Figure 5

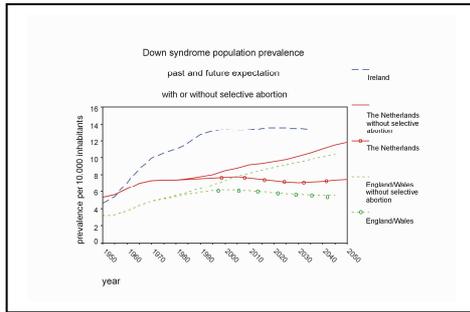


Figure 6

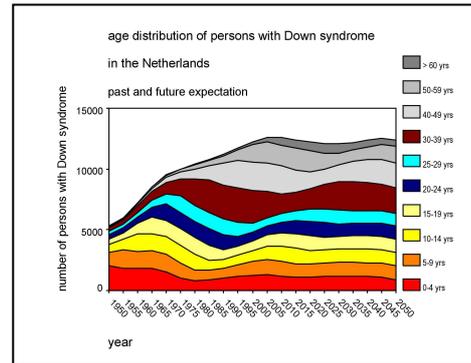


Figure 5 shows model based predicted population prevalence rates for the period 1950-2050 in the three countries concerned. It shows also prevalence estimates, if there had never been any prenatal testing and selective abortion. These figures give an impression of the impact of prenatal services on Down syndrome population prevalence.

The predicted numbers of persons with Down syndrome by age group for the period 1950-2050 in The Netherlands based on the theoretical model are shown in figure 6. These results show that the numbers of 'older' persons with Down syndrome (over 40 years of age) in The Netherlands will reach a peak in the year 2010 with about 4.600 persons. This is twice as much compared to the number of persons with Down syndrome in 1990, implying an increased demand on medical care and counseling.

CONCLUSION A theory based model for Down syndrome prevalence provides supplementary data in situations with a lack of empirical material, for instance in regard to Down syndrome population prevalence in The Netherlands and for recent years for England/Wales and Ireland as well. Moreover, the model can be used for understanding and predicting long-term developments.

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