



National registry and DNA-bank of adults with congenital heart disease



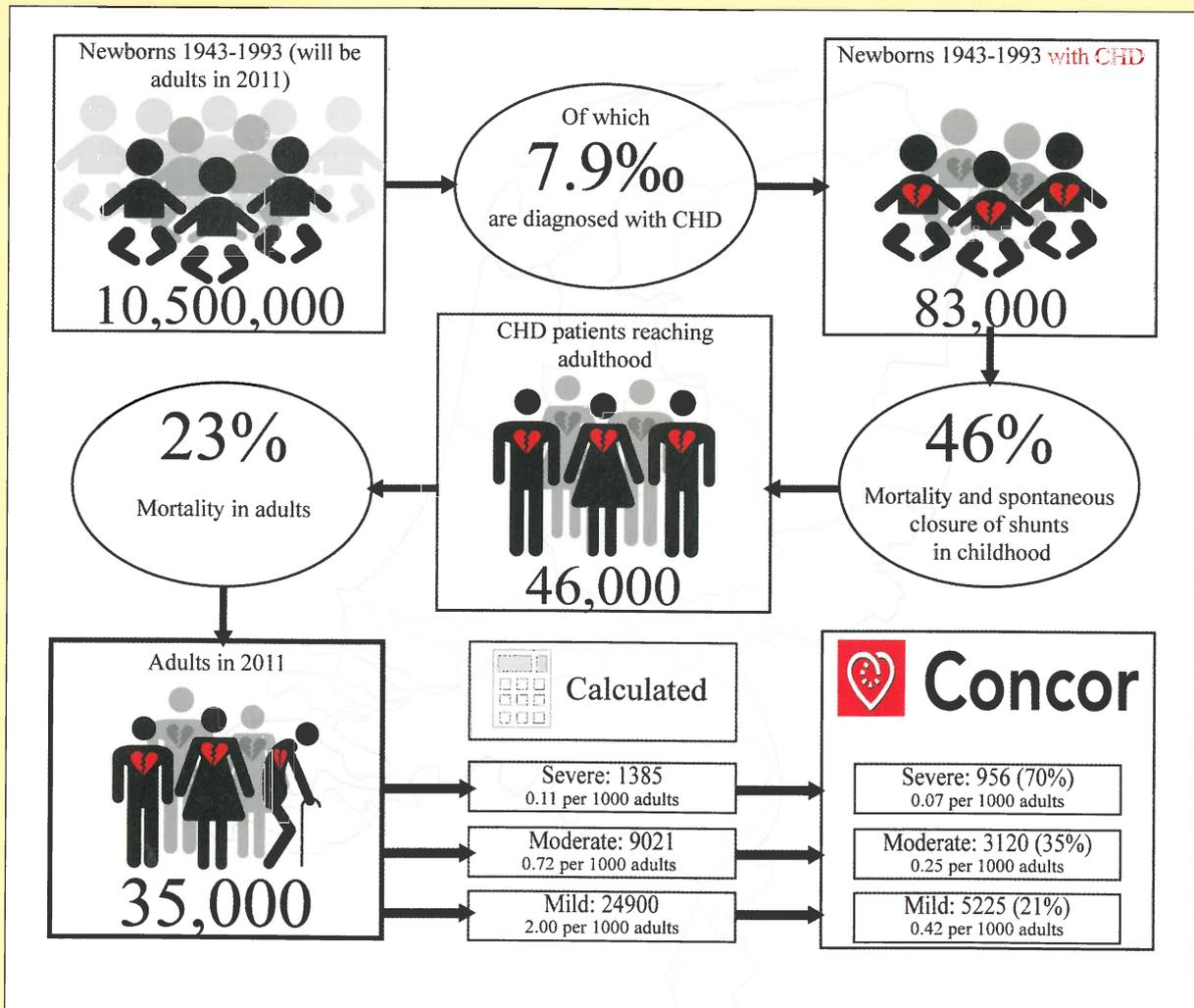
Number of included hospitals: 105
Number of included patients: 12,776

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Background

The prevalence of congenital heart disease (CHD) is unknown. We calculated the number of Dutch adult CHD patients in 2011, using birth prevalence, survival data and CONCOR. Previously published estimates range from 3.6 to 4.8 per 1000 adults.



Conclusion

- 1) ~ 50% of moderate and severe ACHD is included in CONCOR
- 2) Regional centers still hold ~ 5000 moderate and 200 severe ACHD cases
- 3) Lost to follow-up predominantly mild ACHD ■

