



Haemophilia in the Netherlands

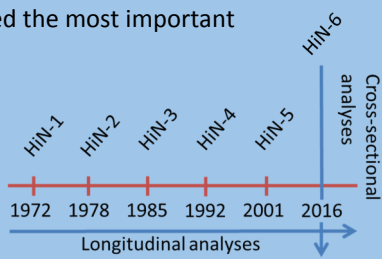
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'Half a century of medical and social data on hemophilia in The Netherlands, 1971 – 2020'

Background

The HiN-6 study is the iteration of a series of national studies conducted among persons with hemophilia (PWH)

The studies have evaluated the most important medical and social developments in hemophilia care over the last half century from 1971 till 2020



Hemophilia

Hemophilia is one of the most well-known rare diseases where one of the clotting factors (VIII/IX) is missing. If untreated it can lead to bleedings in joints and muscles and early death. This can be avoided by prophylactic treatment (2/3 times/week) in severe cases.

Methodology

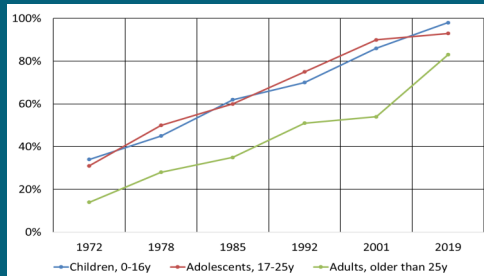
In 2019, a nationwide study was performed among all PWH in The Netherlands. Information on clinical outcomes was obtained through an extensive questionnaire and from medical records of PWH.

Results

The number of PWH that participated in the study over time for the questionnaire were 447 in 1971, 560 in 1978, 935 in 1985, 980 in 1992, 1066 in 2001 and 1011 in 2019. On a total of an estimated number of PWH of 1800 in 2020.

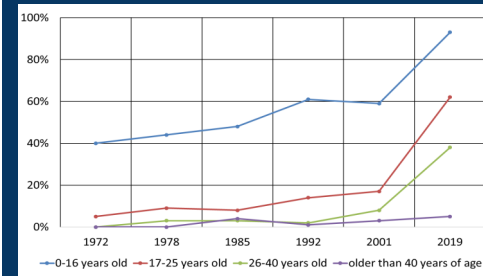
On-demand vs prophylactic treatment

From 1971 to 2020, the proportion of severe PWH on prophylactic treatment increased strongly across all age categories. The strongest increase was seen in PWH aged 0 – 16 years.



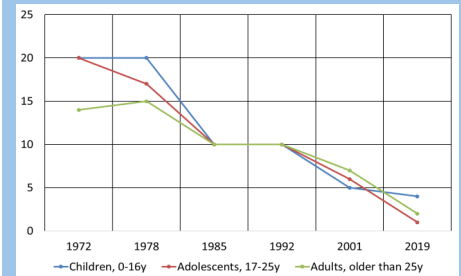
Absence of joint impairment in ankles, elbows and knees

Between 1971 and 2020, an increase was seen in the numbers of PWH that reported having no joint impairment in the ankles, elbows and knees.



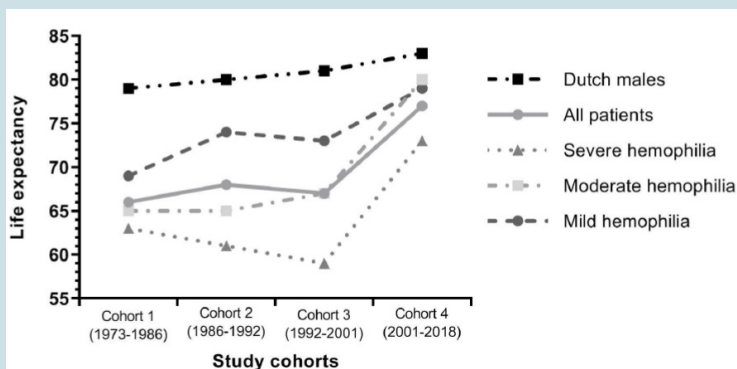
Annual bleed rate

Since 1972, the median annual bleed rate has decreased strongly across all age categories in severe PWH.



Life-expectancy

For all types of hemophilia, we now see an almost normal life-expectancy except for hemophiliacs with an inhibitor (develop antibodies to treatment).



Conclusion

The 'Hemophilia in the Netherlands' study is the only study in rare diseases which followed medical and social well-being of PWH for half a decade. Overall, we see a tremendous improvement of the situation of Dutch hemophiliacs in terms of life-expectancy and daily functioning. In future, the data can be collected more easily through a health app and a biobank in combination with the medical records.

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