

HAEMOPHILIA IN THE NETHERLANDS

6



50 years of research (1971-2019) on the medical and societal circumstances of people with haemophilia in the Netherlands



10 health outcomes
What do patients and professionals consider most important?

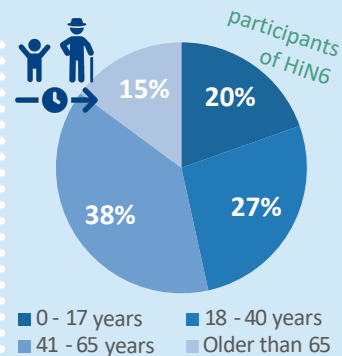
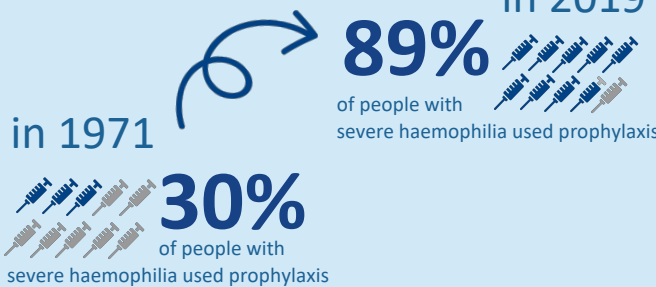
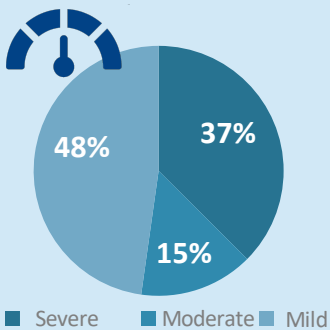
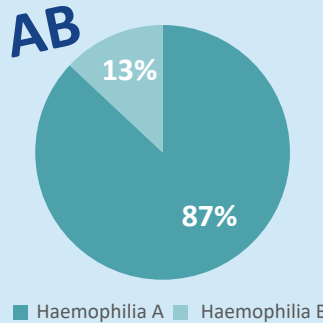
Dear reader,
This infographic shows the most important data which describe the major improvements in haemophilia care over half a century. Curing haemophilia is still the most important desire. This 'Haemophilia in the Netherlands' study is the first study which provides data on the improvement of care in rare diseases worldwide over such a long period.

2.192
registered



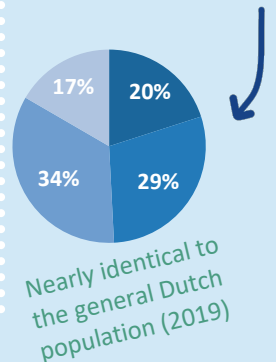
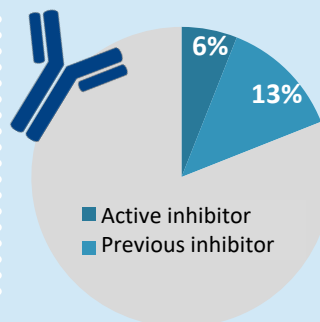
46%
In 2019
responded

participants
1.009

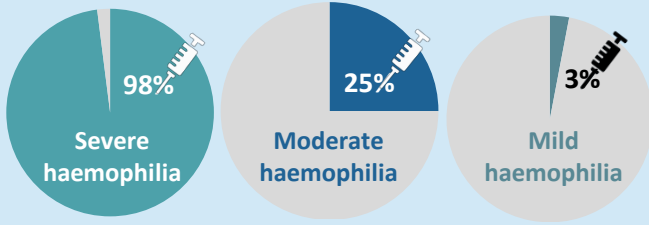


25
in 1971
on average
number of bleeds per person per year (severe haemophilia)

2
in 2019
number of bleeds per person per year (severe haemophilia)



Prophylaxis use among adolescents up to 16 years



In 1978

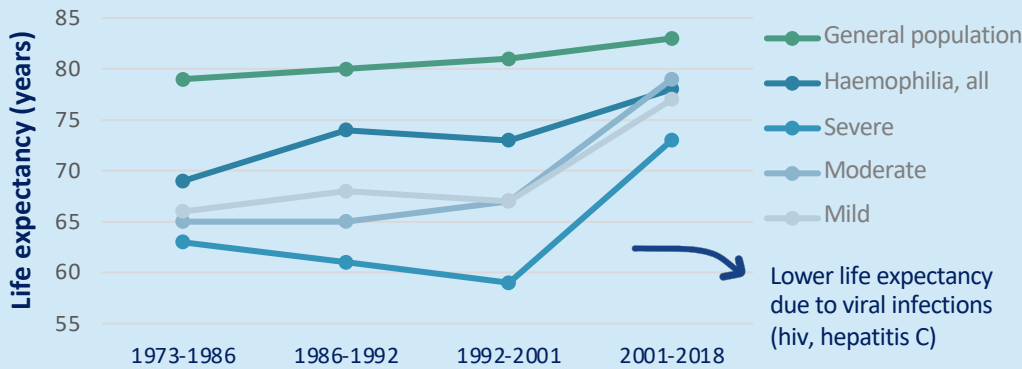
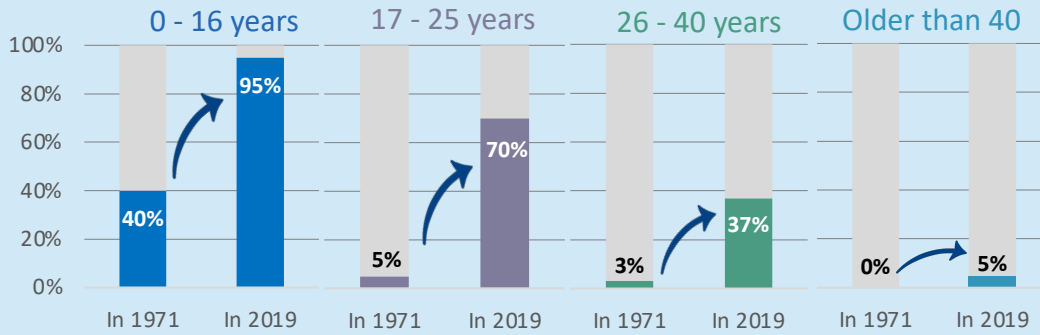
8 years

Average age of onset of prophylaxis use

3 years In 2019

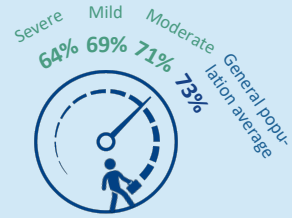


Percentage of people with severe haemophilia **WITHOUT** joint damage in ankles, elbows and knees

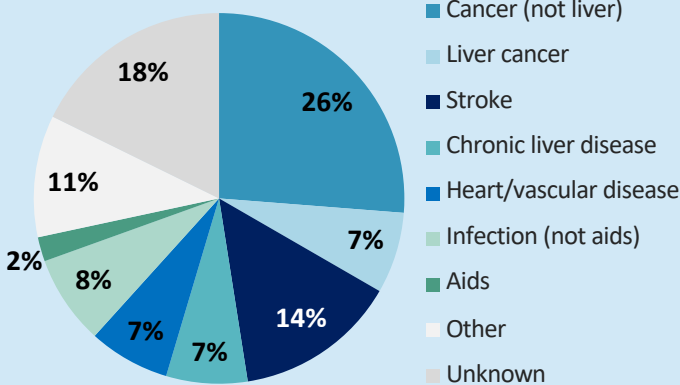


Lower life expectancy due to viral infections (hiv, hepatitis C)

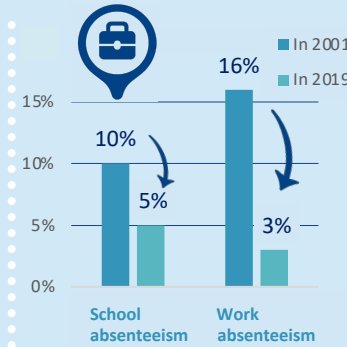
67% of people with haemophilia has a paid job



Causes of death among people with haemophilia (2001-2018)



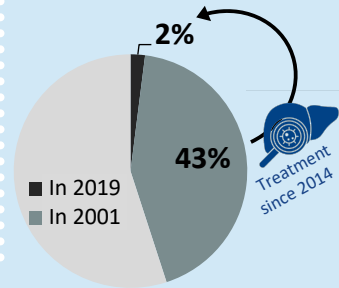
130 - 170 people with haemophilia were infected with hiv in the 1980s
20 - 30 of them are still alive



1 in 4.000 Dutch men suffer from haemophilia



Hepatitis C prevalence



Of people infected with hepatitis C in the past,



still suffer from liver problems