

Farewell Symposium Evert-Ben van Veen

**The learning health care system
and patients' interests:**

The 'Hemophilia' perspective

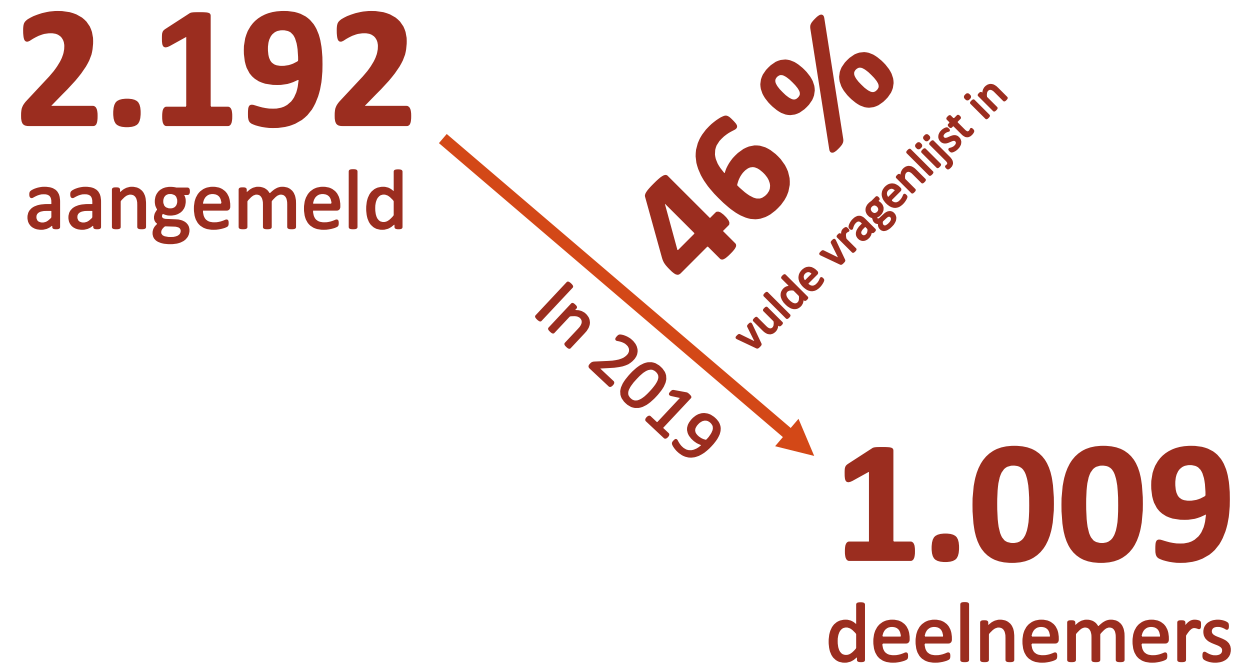
Cees Smit, Patient Advocate & LUMC, dept. Epidemiology



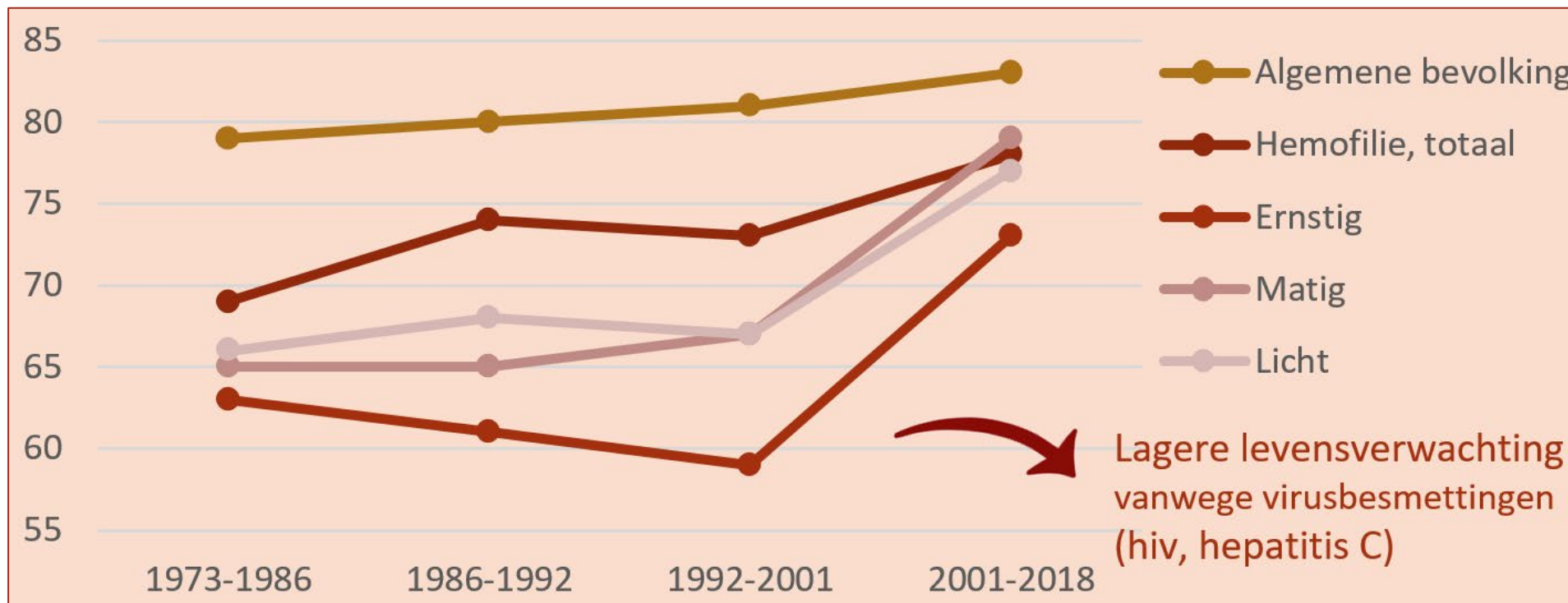
Hemophilia in the Netherlands – part 6

50 YEARS OF RESEARCH (1971 - 2019)
INTO THE MEDICAL AND SOCIAL CIRCUMSTANCES
OF PEOPLE WITH HEMOPHILIA IN THE NETHERLANDS

Participants in 2019



Life-expectancy



Severe hemophilia

in 1971



30%

van de mensen met ernstige hemofilie gebruikt profylaxe

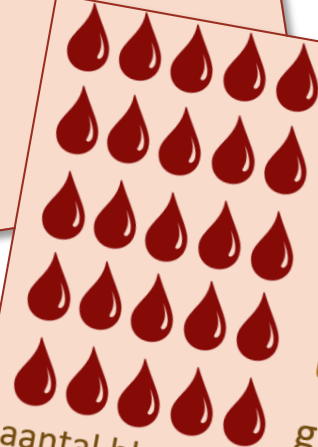
in 2019

89%



van de mensen met ernstige hemofilie gebruikt profylaxe

in 1971



25

gemiddeld aantal bloedingen per persoon per jaar bij mensen met ernstige hemofilie

in 2019

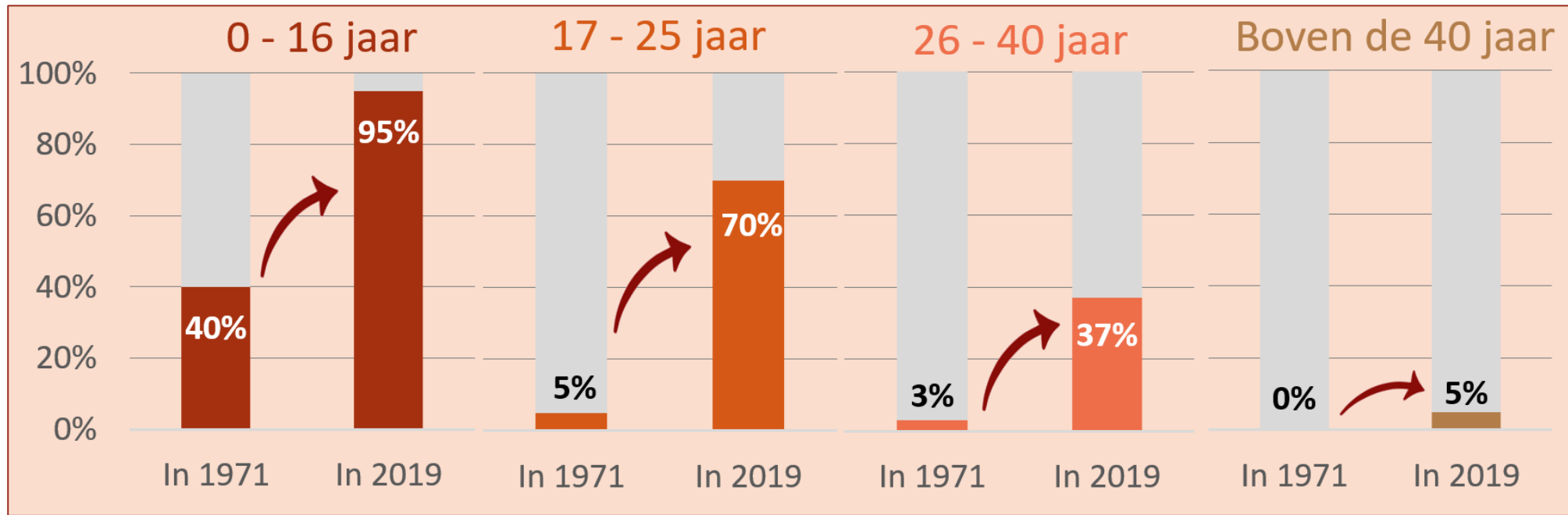
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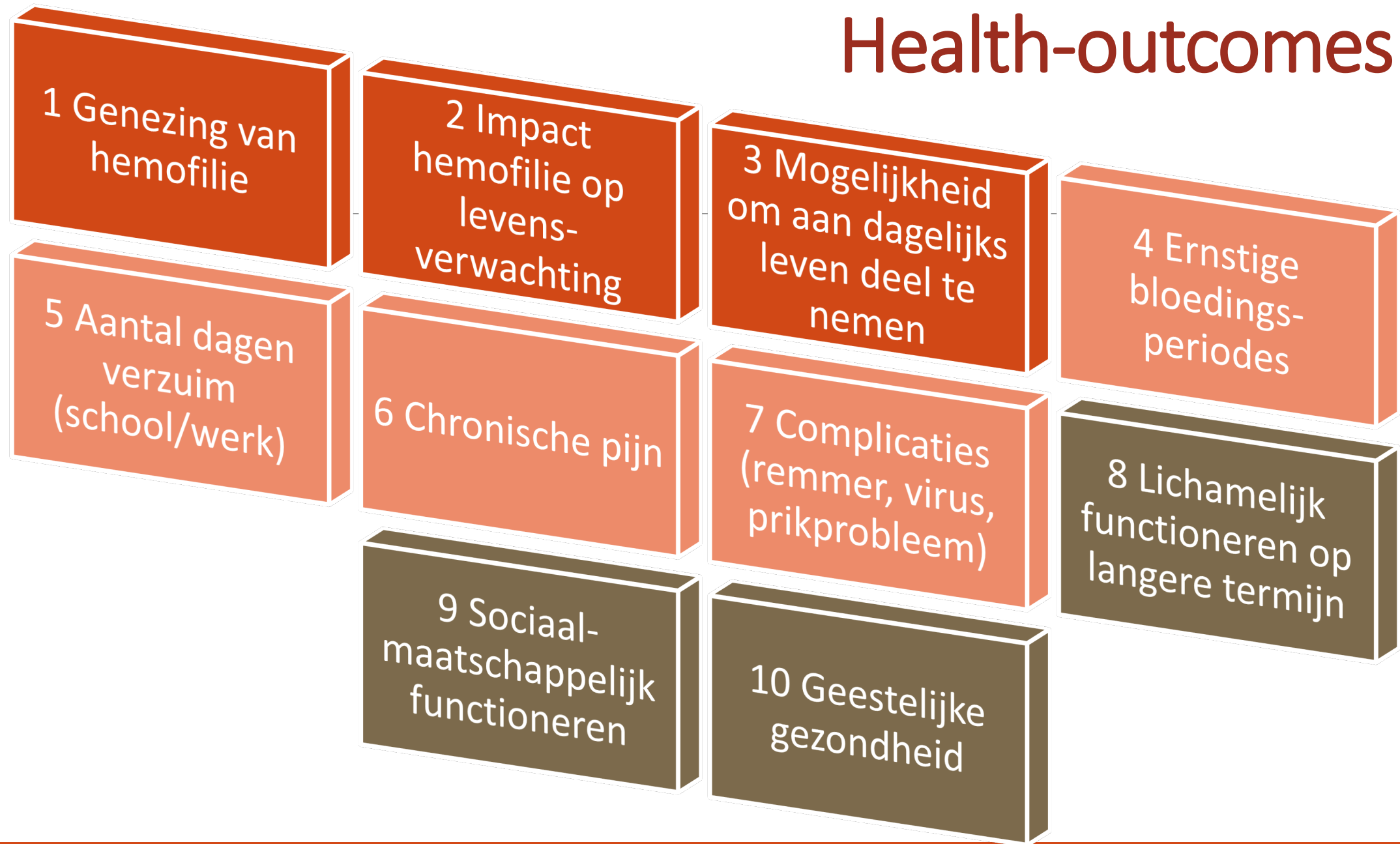
bloedingen per persoon per jaar bij ernstige hemofilie

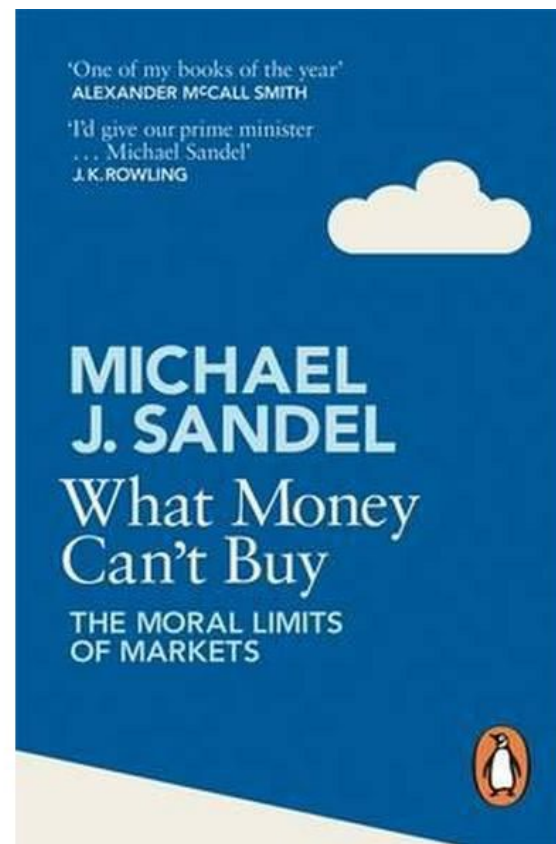


People with severe hemophilia without joint damage in ankles, elbows and knees



Health-outcomes





National hemophilia register

All participants in HIN are now in a computer-register and biobank (only for this research project)

Our HiN-6 project seriously delayed because of difference of opinions between UMC's

All people with bleeding disorders are in a national register HemoNed

Personally, I would have favoured the CF-approach as example for this, but!

We have now substantial problems with app development for daily treatment

Hemophilia treatment centres do not put their data directly in HemoNed and results of clinical trials of new products (e.g. gene therapy) are industry registers (secrecy of adverse events)

My own digital environment

Limited, only 'Mijndossier' of my own medical center, very satisfied with that

But lab results needs clarification in older patients with comorbidities

No interest in larger digital 'Personal Health Environment' (PGO)

Enthusiastic about future (possible & responsible) exchange of 'Mijndossier' with other hospitals and other countries (travelling)

European Patients' Forum (EPF) infavour of European Health Data Space (Infographic)