



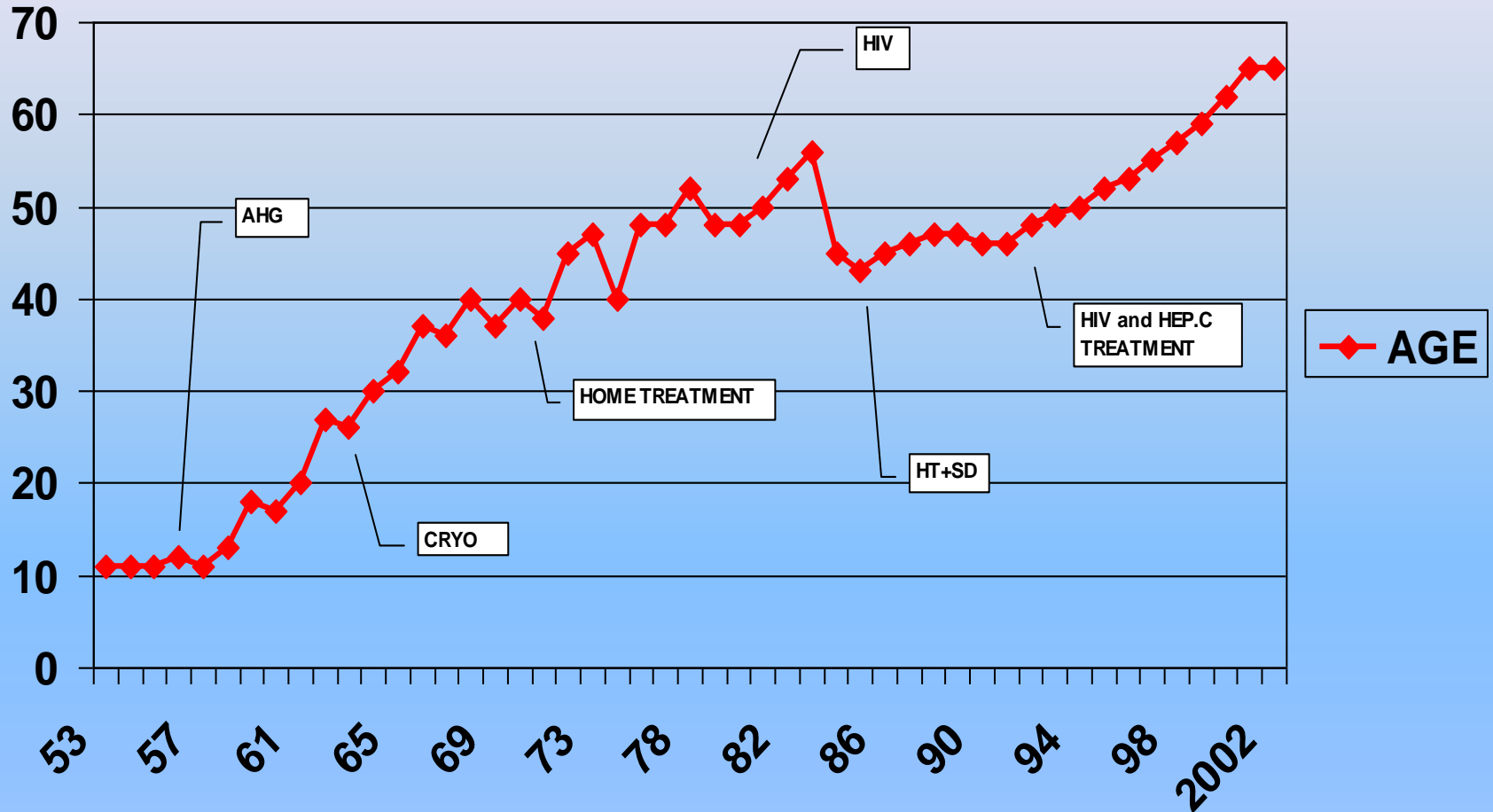
“A LONG LIFE WITH HAEMOPHILIA” **– results from the survey**

Danish Haemophilia Society





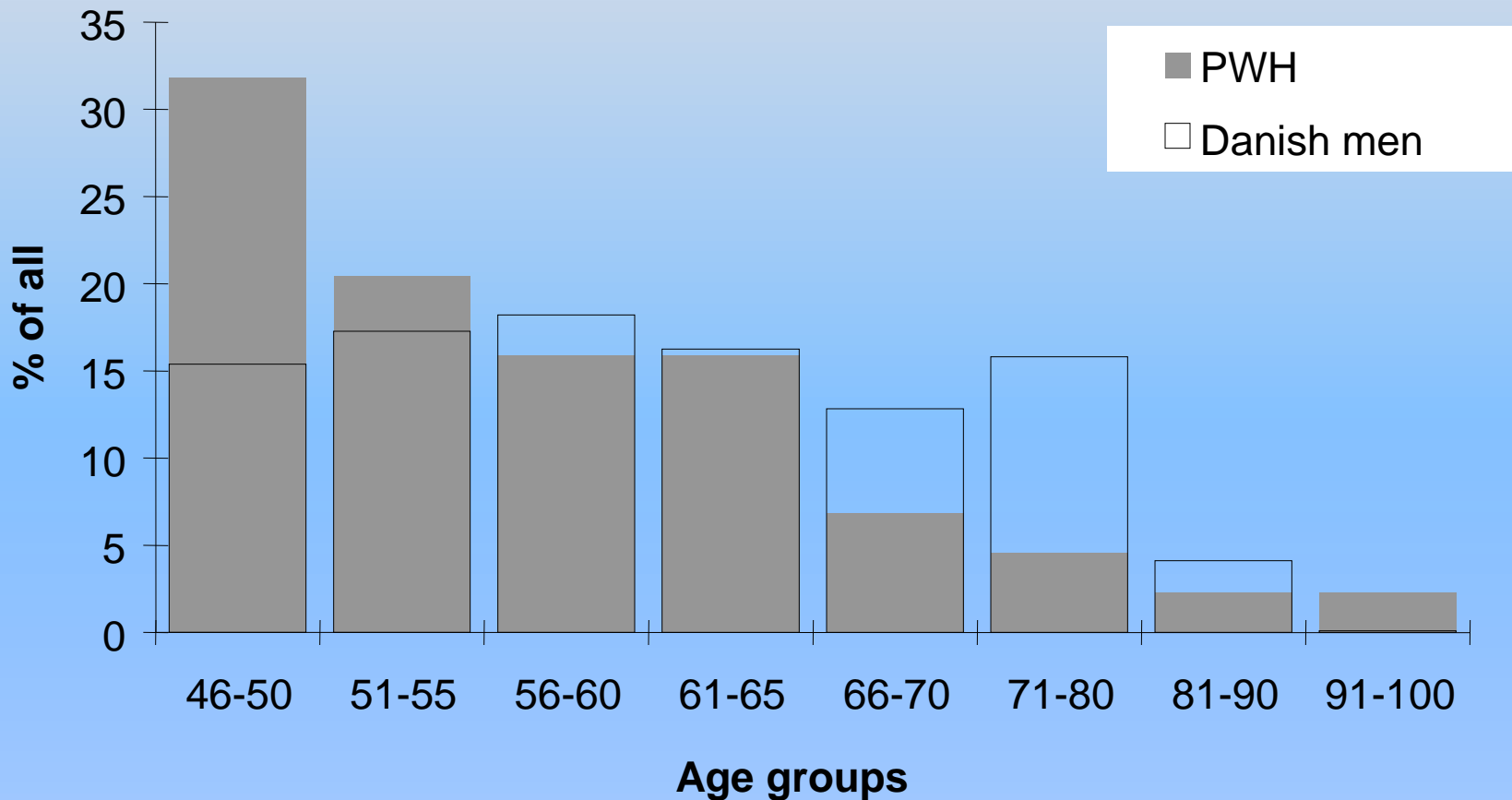
Age at death in persons with haemophilia in USA





Age distribution

Age distribution in PWH above 45 compared to danish men





Social and professional situation

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Education

- More PWH s has no vocational training (26 pct. vs. 18. pct)
- More PWH s has medium or higher education (60 pct. vs. 25. pct.)

Labour market situation

- PWH s are active in the labour market
- Almost as many PWH s holds jobs without compensatory arrangements (59 pct. vs. 67 pct.)
- Might retire a bit early, but easier to motivate to stay on

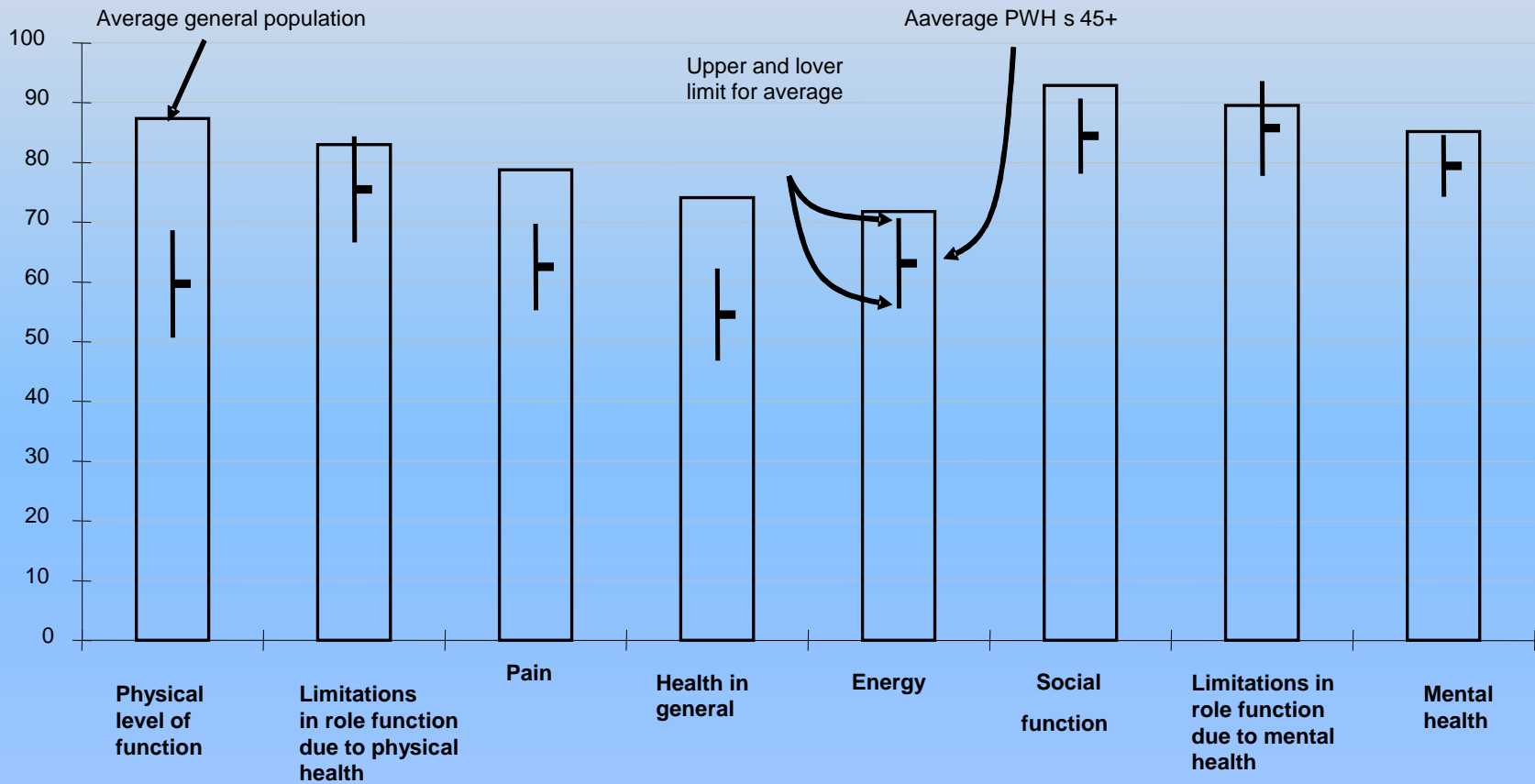
Family life

- More PWH s are single /living alone
- It is more difficult for PWH s to get help now than before



Status of Health

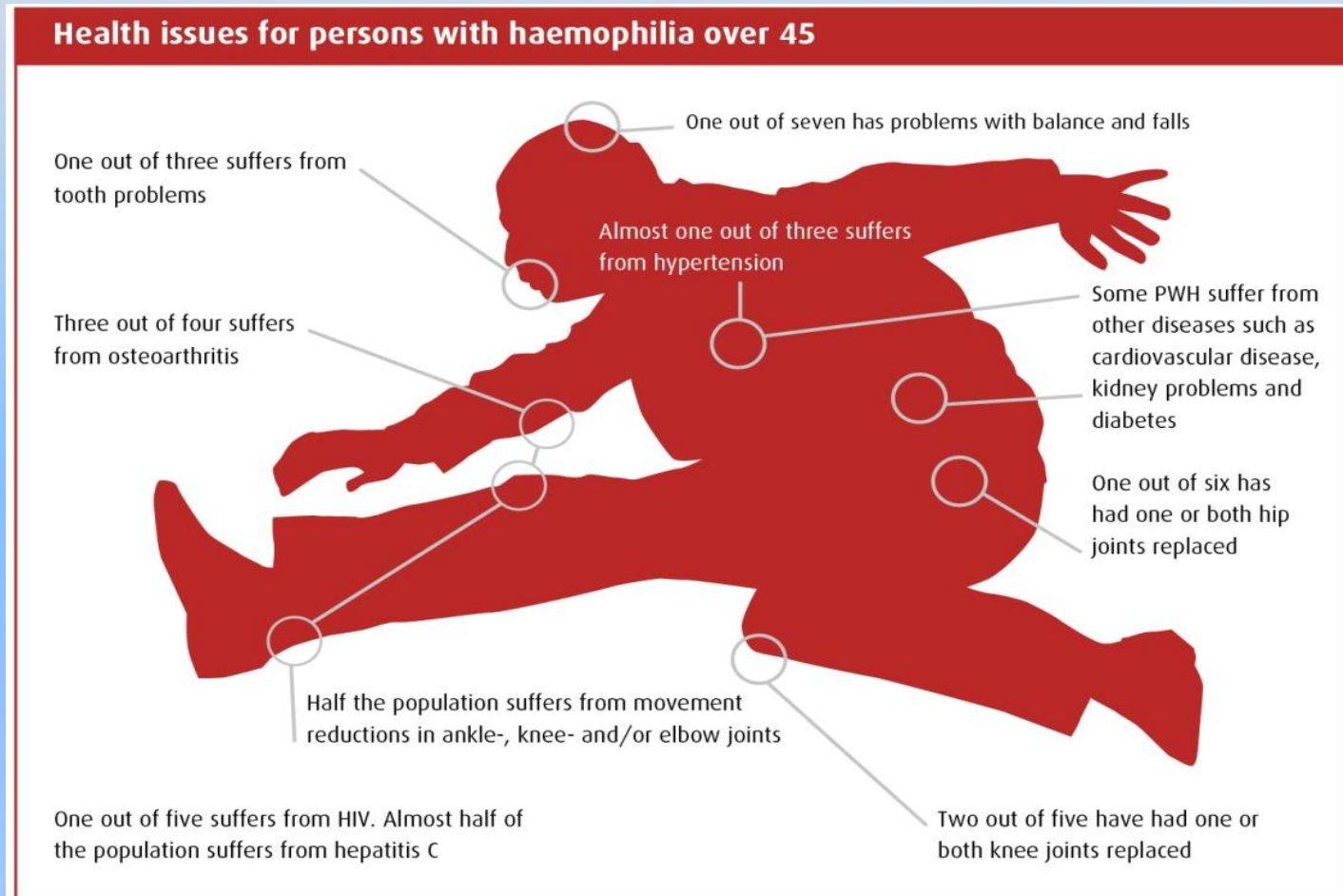
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Ageing and illness in haemophilia

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Some limitations - and pain

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Limitations:

- In physical demanding activities (70 pct. vs. 19 pct. very limited)
- Also when f.i. bending down / bending knees (51 pct. vs. 6 pct. very limited)

Pain:

- No pain is rare (14 pct. vs. 43 pct.)
- Very strong pain much more common among PWHs (5 pct. vs. 2 pct.), as well as medium and light pain (56 pct. vs. 27 pct.)



Concerns about the future

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<i>Lately, I have been worried about:</i>	<i>Very much or somewhat concerned</i>	<i>Not concerned</i>	<i>Not relevant</i>
To suffer more from pain in the future	23	16	4
To become unable to take care of my-self in every day life	22	18	4
To have to get (more) joints replaced	21	16	5
Not being able to do my hobbies	15	19	9
To become unable to visit family and friends	14	23	7



Fields of action - 1

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- **Daily life**

- Improve dialouge with the social system
 - Social Profile
 - Virtual Toolbox

- **Working life**

- Focus on keeping the PWH on the labour market, special arrangements and terms for employment.
 - Social Profile for social workers on employment rules, possibilities and the needs and limitations of the older PWH



Fields of action - 2

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Danmarks Bløderforening

- Stat os
- Nyheder
- Landsindsamling
- Bløder sygdom
- ITP
- Livet med Bløder sygdom
- Personlige beretninger
- At stikke selv
- Bærer og graviditet
- Gift/kæreste med en bløder
- Hjælp til børn
- Inhibitor
- Johæggning
- Over 50 år
- At være på arbejdsmarkedet
- At forløse arbejdsmarkedet
- Fysisk aktivitet
- Dårlige led
- Smarter og bekymringer
- Veltraad
- Hjælpe midler
- Hjælp i særlige tilfælde
- Kontakt med andre?
- Ræjs
- Sport
- Udskiftning af led
- Venekateter

Velkommen til den virtuelle værktøjskasse for ældre blødere

For første gang i verdenshistorien har blødere i dag udsigt til at blive lige så gamle som den almene befolkning. Danmarks Bløderforening har udarbejdet en virtuel værktøjskasse, som skal hjælpe de ældre blødere i dette udforskede land.



Der er opstået en helt ny generation af ældre blødere. For første gang nogensinde har blødere i dag udsigt til at blive lige så gamle som den almene befolkning. Men hvad giver det af muligheder og problemer for den enkelte bløder og hans pårørende, når alderens erfaring og skavanker meder sig? Det er et udforsket land, som Danmarks Bløderforening har sat sig for at undersøge.

Derfor har Bløderforeningen i perioden 2008-2010 afviklet projektet *Bløderliv under forandring*. Projektet er finansieret af Socialministeriets støttepulje.

Virtuel værktøjskasse

I løbet af projektet har vi arbejdet med at beskrive den ny generation af ældre blødere og udvikle redskaber, der giver bedre mulighed for at leve et liv med arbejde, familie og aktivt medborgerskab så længe som muligt. Et af redskaber er denne virtuelle værktøjskasse.

Værktøjskassen præsenterer dig for den ny viden, projektet har frembragt, personlige beretninger om det at blive ældre med en blødersygdom og nyheder på den medicinske front.

Værktøjskassen vil løbende blive opdateret. Det er som nævnt et udforsket land, vi bevæger os ind i, og der er stadig meget, der skal afsløres, og nye muligheder der skal åbnes.



Fields of action - 3

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- **Health**

- The need and importance of physiotherapy, adequate treatment of bleedings and pain
 - Workshop on annual meeting on this issues, that score high in the survey
 - Create publication on physical training for elderly haemophiliacs

- **In general**

- Share information and experience of the challenges as an older PWH between patients, family members, health care providers and social security workers.
 - Increase the Society's engagement in informing and advising older haemophiliacs.
 - Improving networking through different activities.



In Conclusion

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- We now have new knowledge of the ageing PWH s – and of what we don't know how to handle – yet!
- We invite other NMO's to make similar and other investigations to map the situation in Europe, and to develop common fields of action



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Acknowledgements

- This presentation is based on the survey "A long life with haemophilia" as presented by boardmember of the Danish Haemophilia Society dr. Theis Bacher on several occasions.