



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

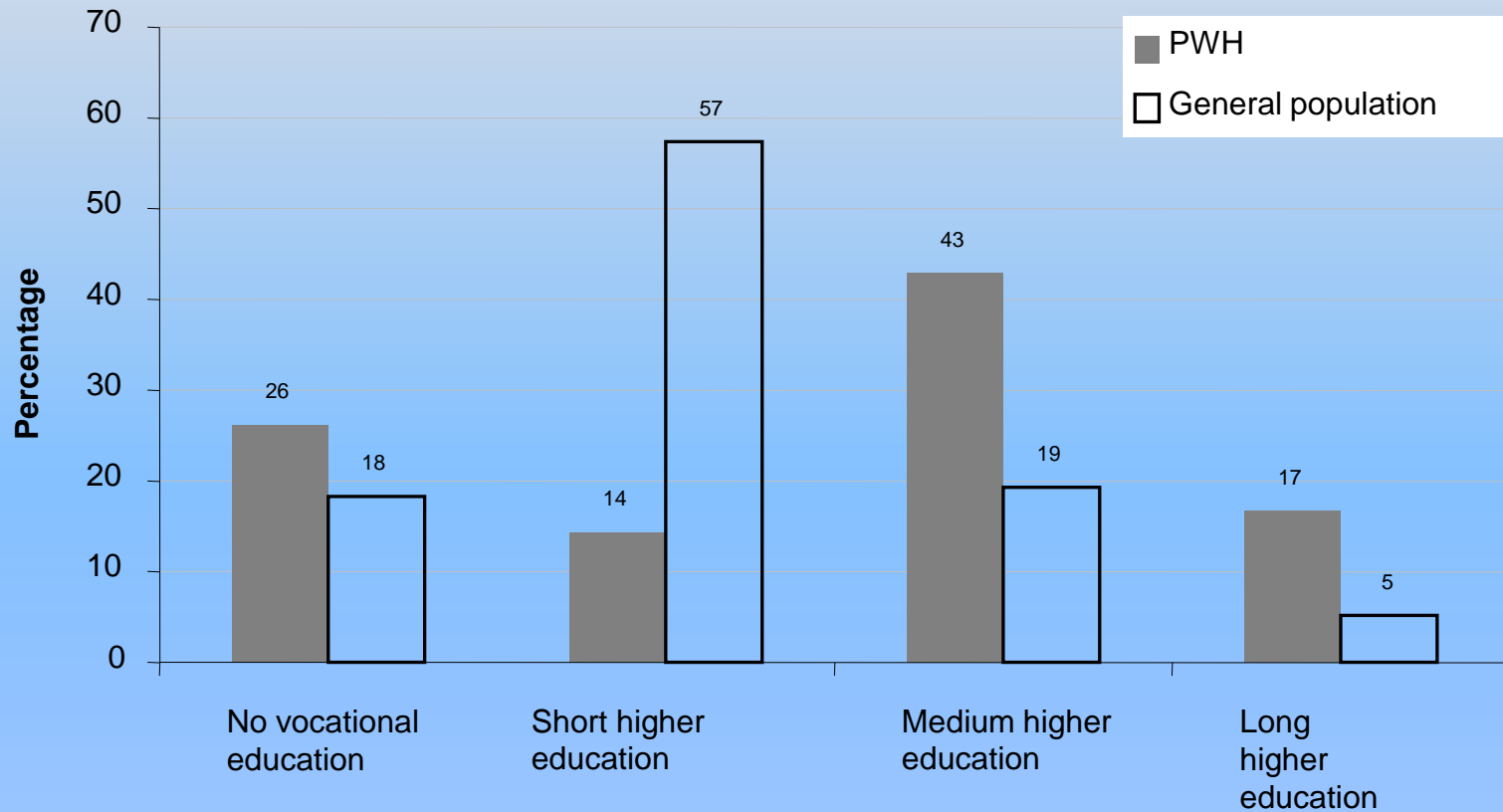
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# Education

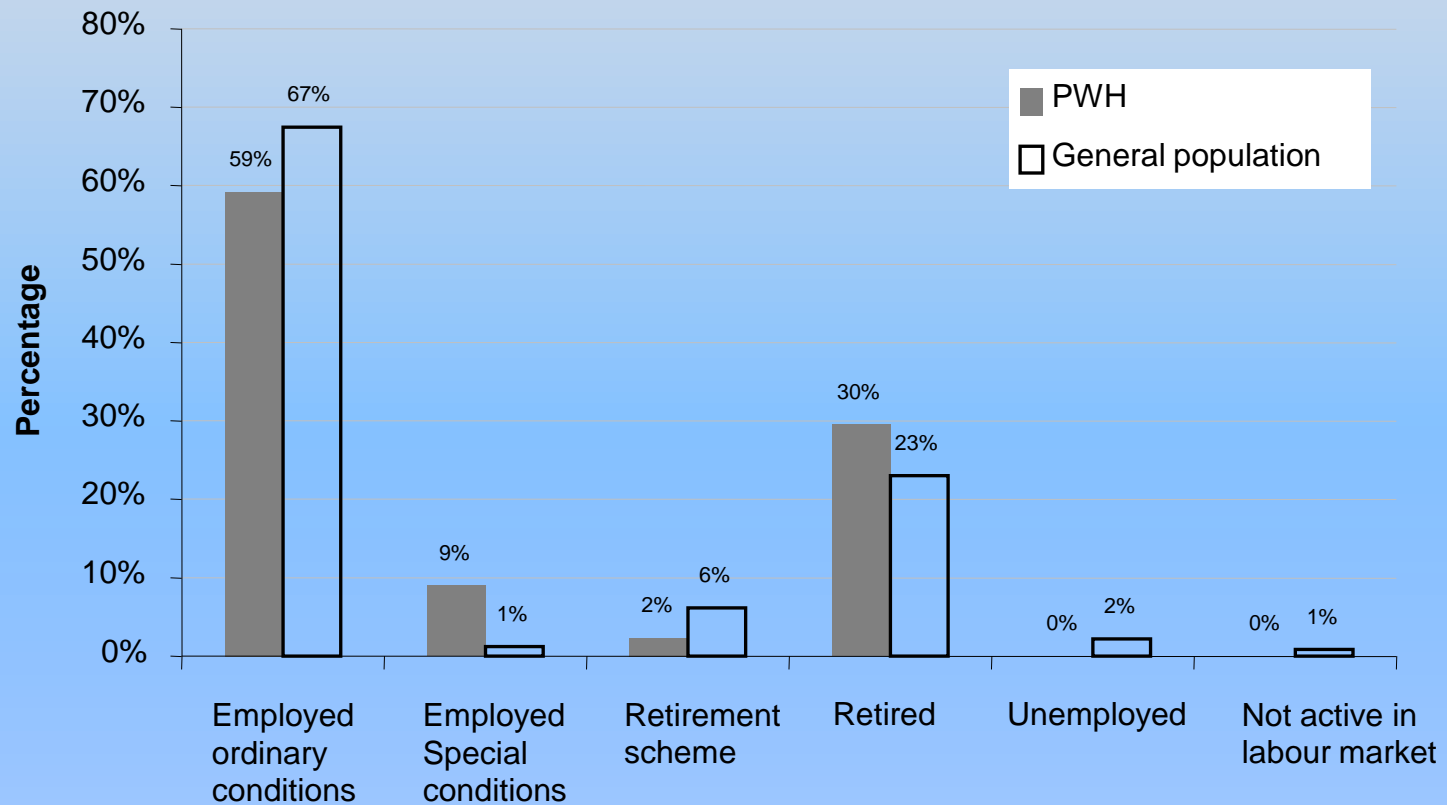
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# Employment Status

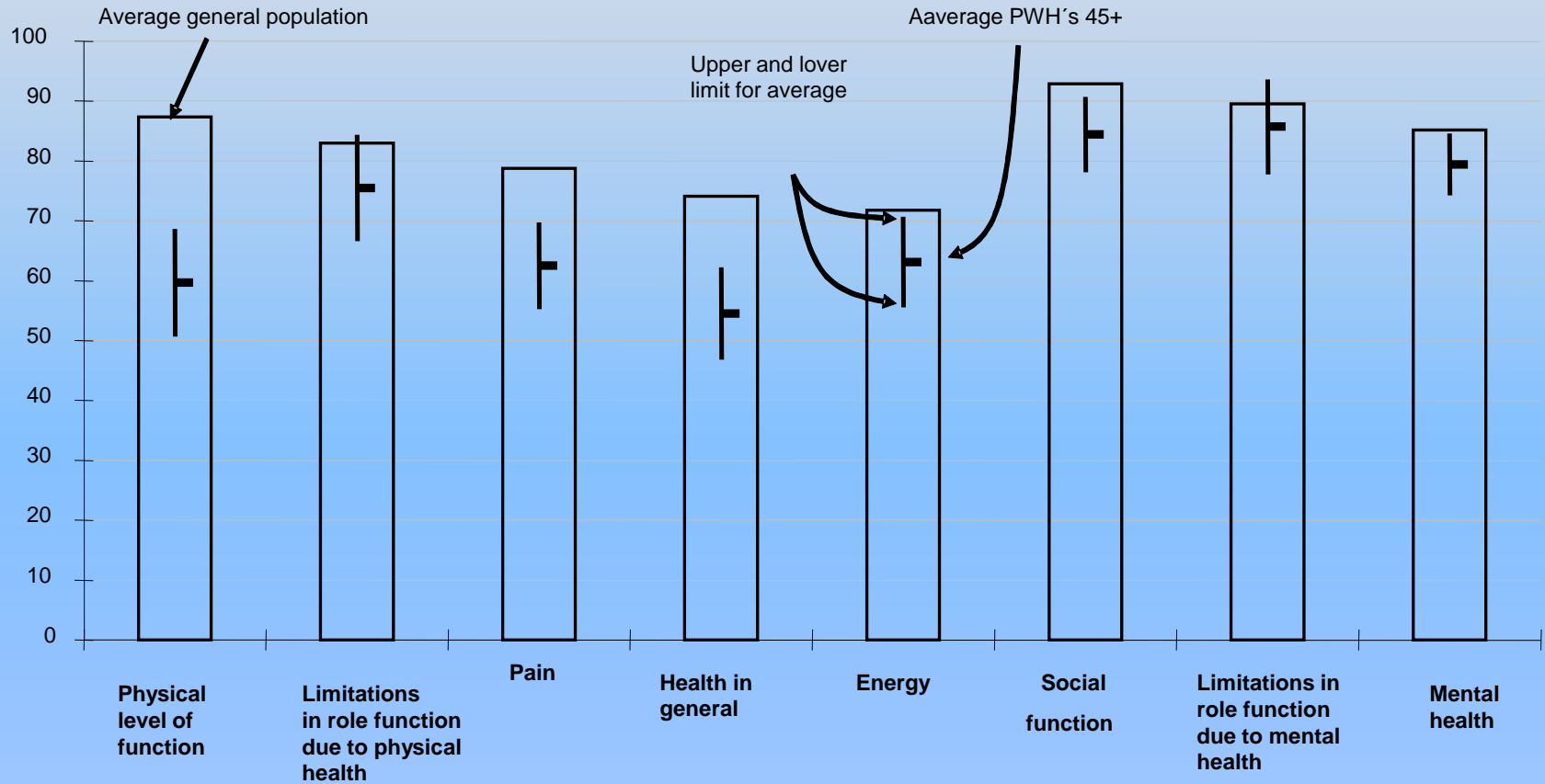
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# Status of Health

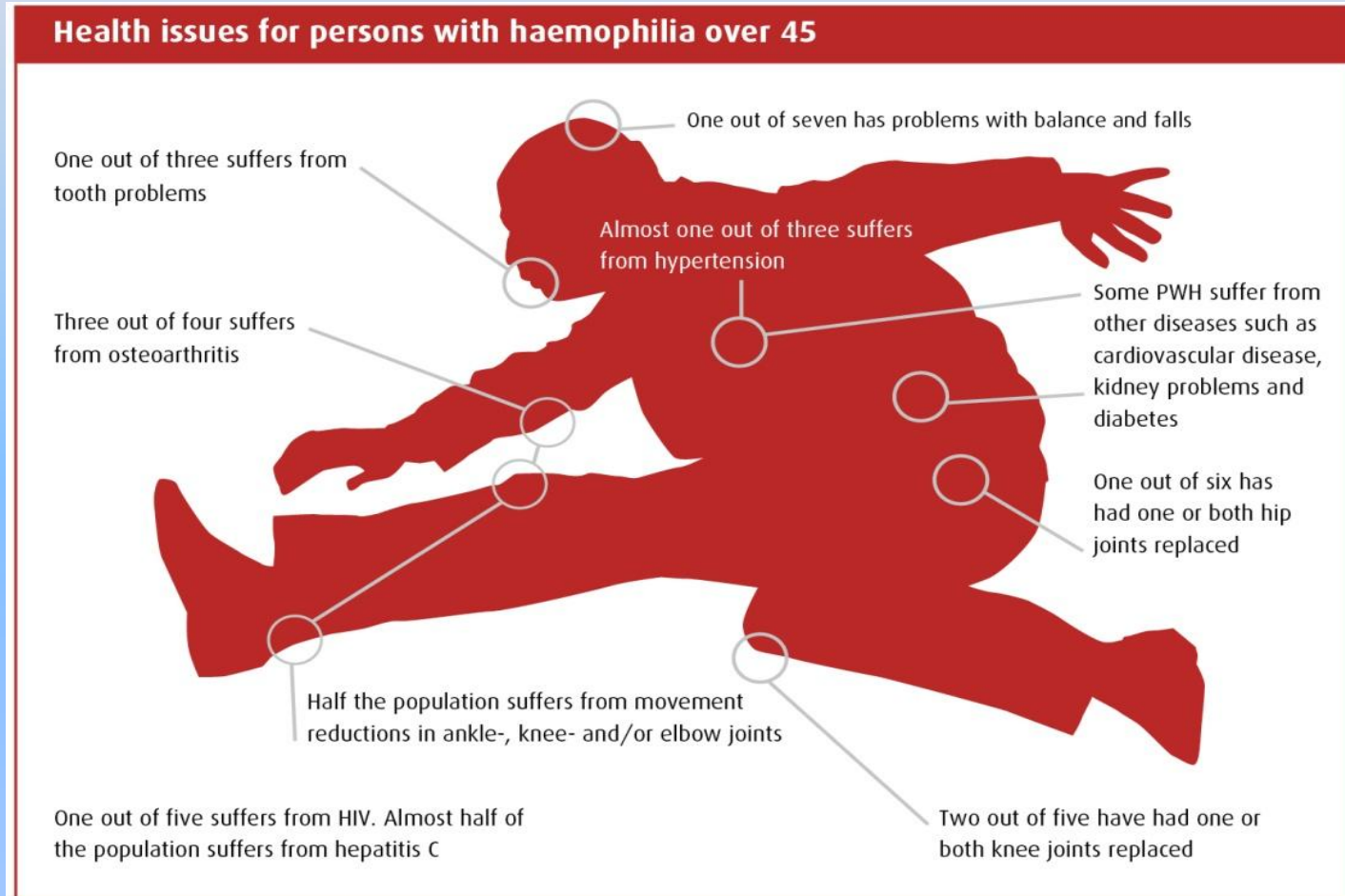
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# Ageing and illness in haemophilia

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# 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 (50%)	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

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- **Daily life**
  - Improve dialouge and connection to the social system.
- **Working life**
  - Focus on keeping the PWH on the labour market, special arrangements and terms for employment.
- **Health**
  - The need and importance of physiotherapy, adequate treatment of bleedings and pain.
- **In general**
  - Share information and experience on the challenges as an older PWH between patients, family members, health care provider and social security workers.



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## In Conclusion

We would like to invite other NMO's  
to make similar and other  
investigations to map the situation  
in Europe, and to develop common  
fields of action