Outcome measures for older people with haemophilia

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28 November 2016

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Life expectancy in haemophilia

1830-1920	Sweden	severe	11
1920-1940	Sweden	severe	23
1940-1960	Sweden	severe	28
1930-1957	Sweden	severe	25
1960-1980	Sweden	severe	57
1975-1980	United Kingdom	severe	69
1973-1986	The Netherlands	severe	63
		moderate	65
		mild	69

(Larsson, Br J Haematol 1985; Ramgren, Acta Med Scand 1962; Rizza, BMJ 1983; Rosendaal, Br J Haematol 1989)

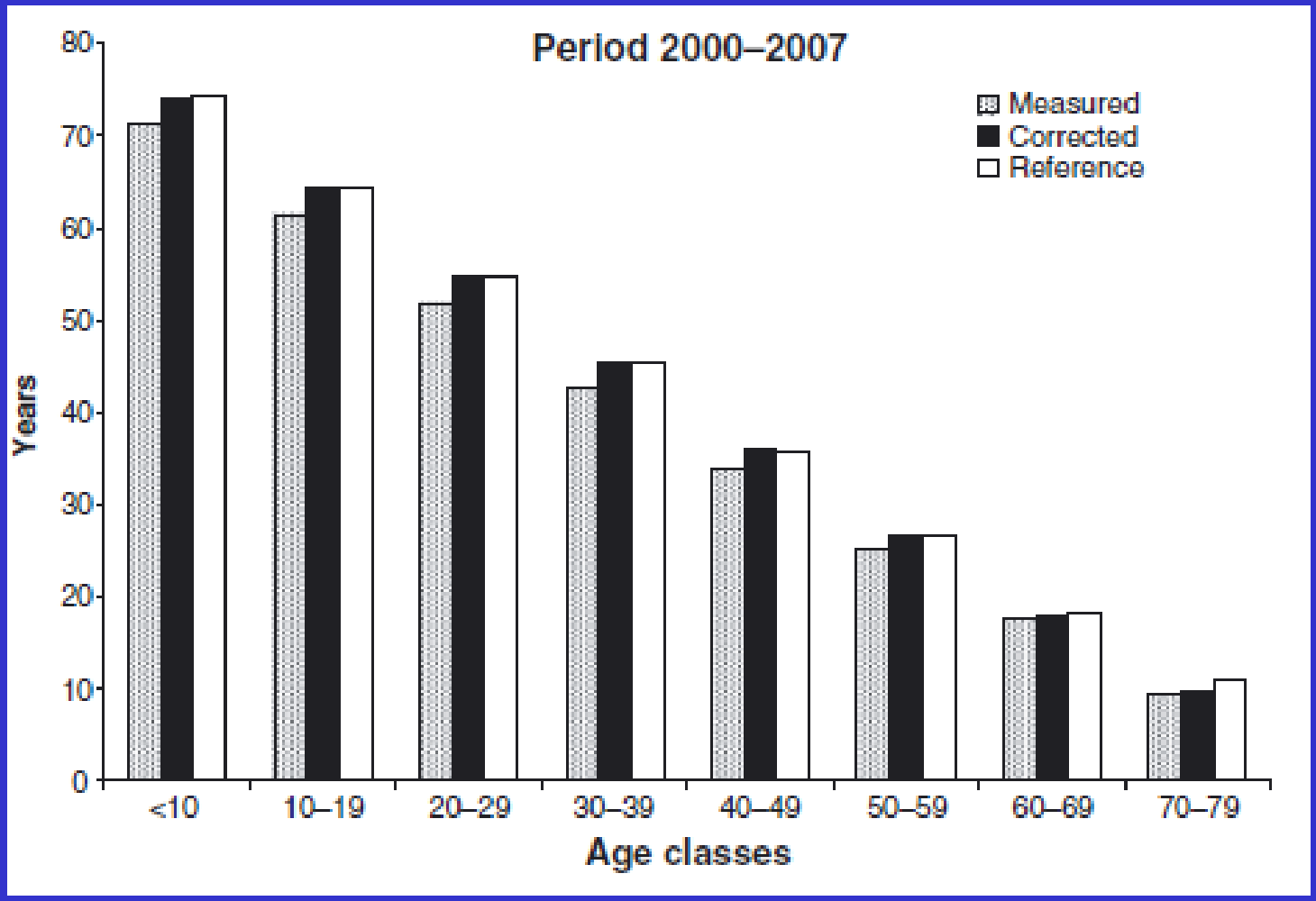
Life expectancy (1992-2001)

	All
All	67
severe	59
moderate	67
mild	73

(Plug, J Thromb Haemost 2006)

(Dutch men: 76 yr)

Similar data from Italy



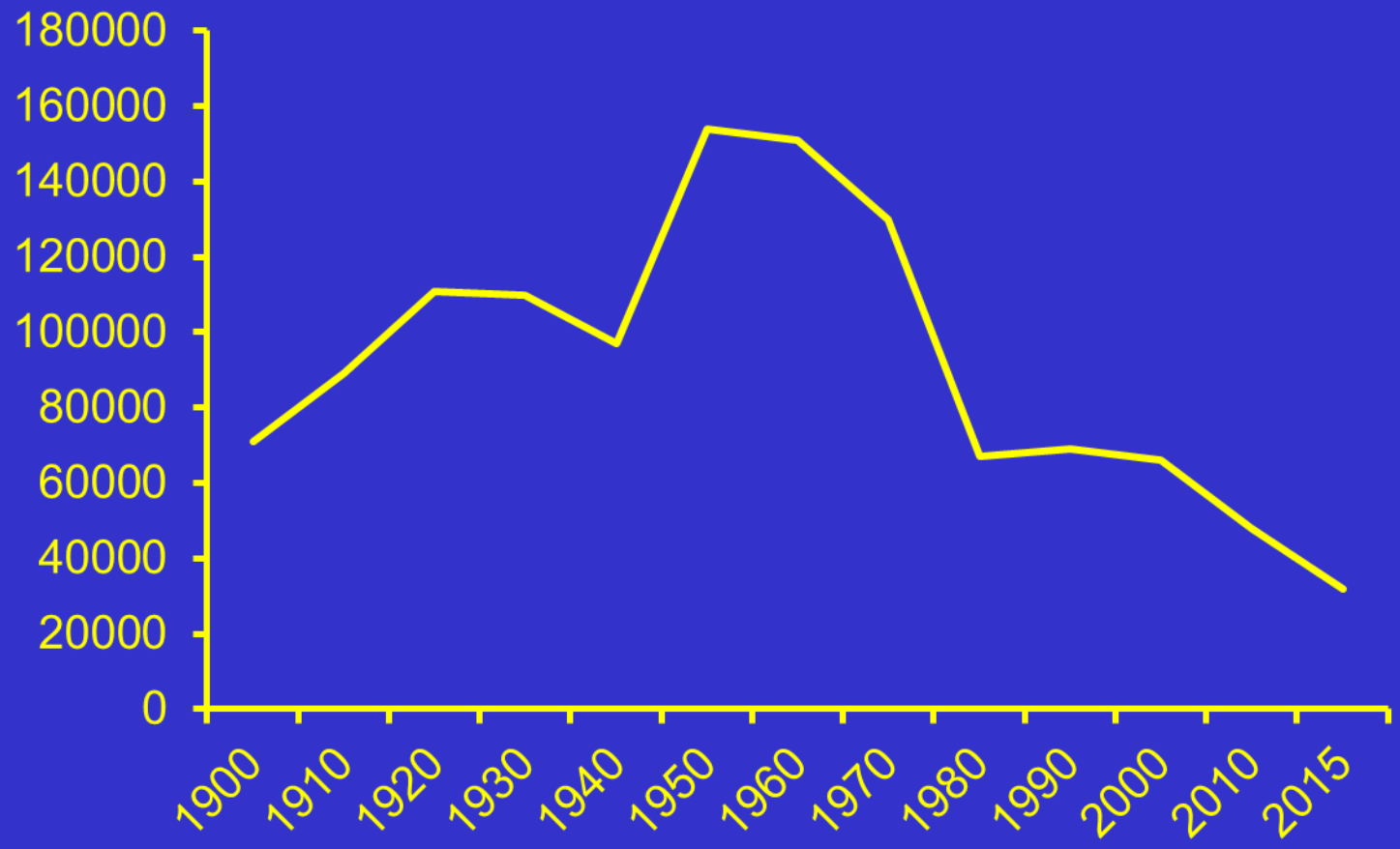
(Tagliaferri, Haemophilia 2010)

Consequences

- consequences of increased life-expectancy: more older patients

- age-distribution result of
  - current and past birth rates
  - current and past death rates

Birth excess



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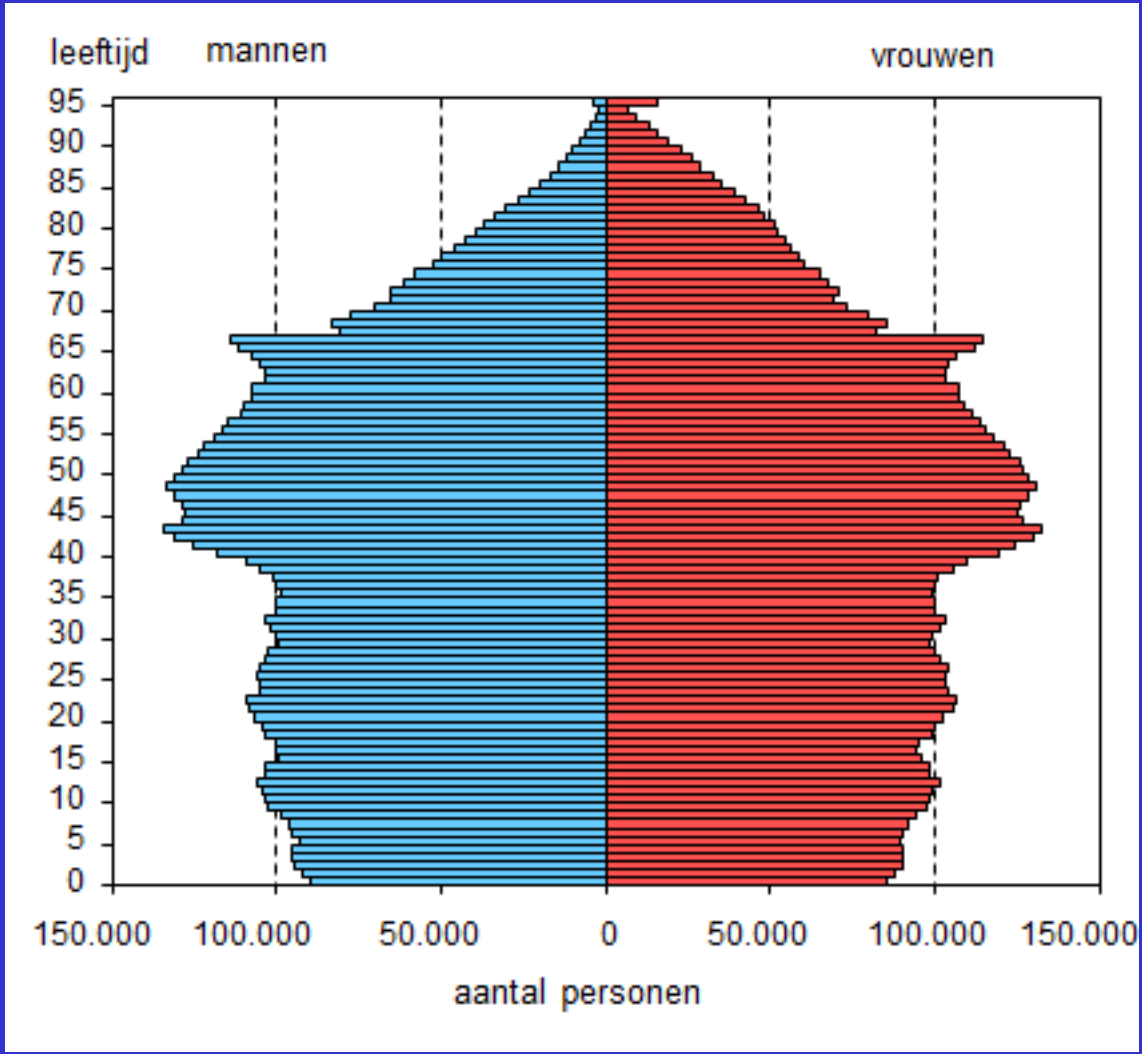
General population 2015



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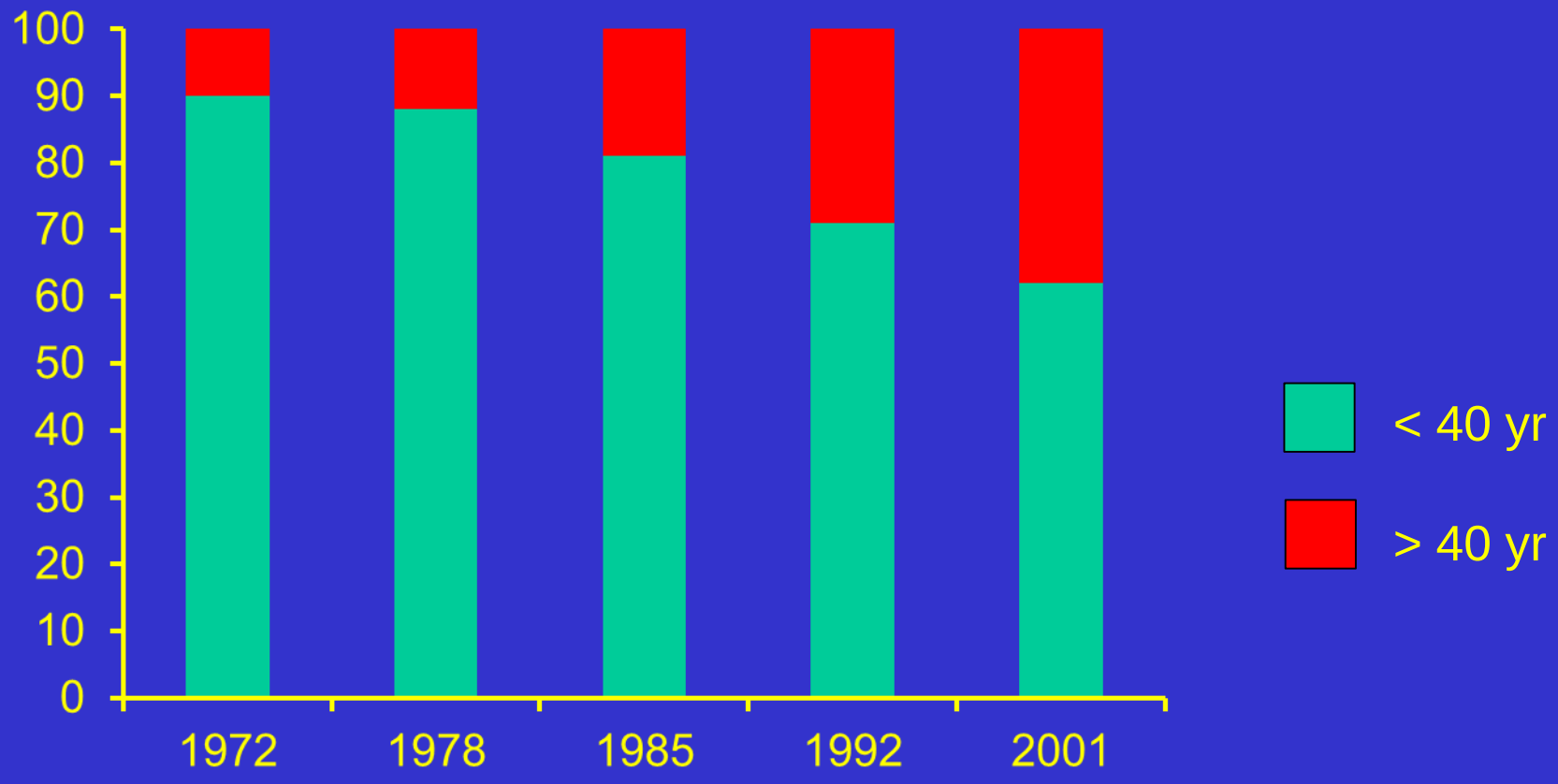
Haemophilia population



(Plug, Blood 2004)

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Conclusion

- life-expectancy has increased much
  - similar to population
- consequence: age-distribution changing
  - proportionally more older patients
- age distribution will vary from place to place
  - dependent on birth rates last decades (baby-boom)
  - dependent on previous excess deaths due to HIV and HCV
  - dependent on reproductive choices

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Current haemophilia population

- born before 1960
  - 55+
  - major sequelae fro haemophilia
  - viral infections
- born 1960-1990
  - 25-55 yr
  - moderate sequelae haemophilia
  - viral infections
- born 1990-2016
  - <25 yr
  - mild sequelae haemophilia
- born after 2016
  - generation that may be cured

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Changing perspectives

The 50-year old patient with severe haemophilia

- in 1965
  - was not alive
- In 1990
  - severe arthropathy
  - HIV
- in 2016
  - moderate arthropathy
  - HIV, HCV
- In 2040
  - No or mild arthropathy
  - No viral infection

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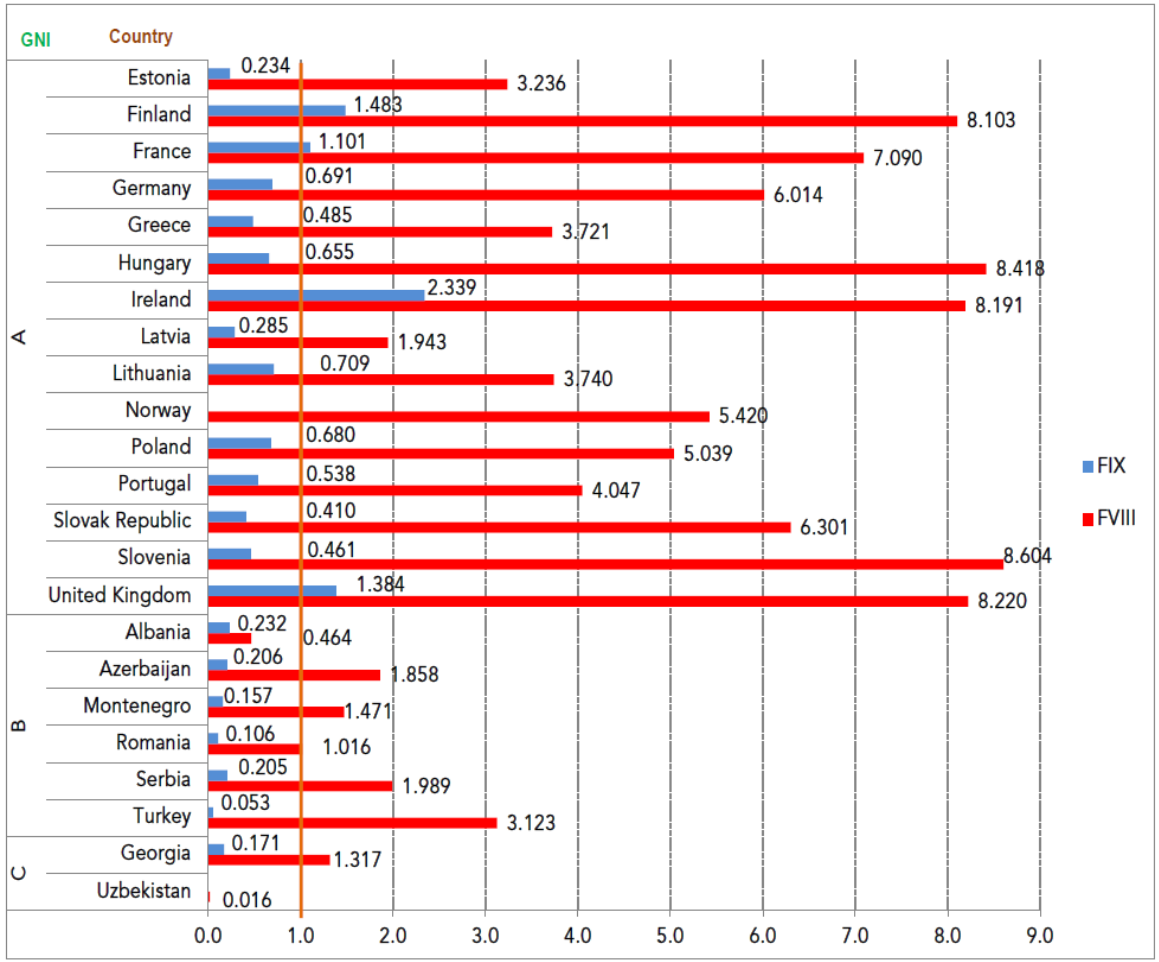
There is not one Europe

C4. Mean per capita factor VIII and IX use in 2014 – regional and GNI comparisons of IU/total population: Europe



(WFH, 2014)

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The ageing patient

- the bleeding disorder
  - type and frequency of bleeding
- the ageing process
  - diseases of advancing age
- sequelae of previous events
  - viral infections
  - arthropathy
- interactions between all the above

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Uncharted territory

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The bleeding disorder

European CHESS project (n=541)

annual bleeding rate

18-30	9.99
31-40	10.85
41-50	12.38
51-60	13.85
61+	13.42

(O'Hara, personal communication)

Diseases of advancing age

- malignancies
- atherosclerotic diseases
  - atrial fibrillation
  - ischaemic stroke
  - myocardial infarction
  - heart failure
- Alzheimer diseases
- chronic obstructive pulmonary disorder (COPD)
- osteoarthritis
- frailty
- ….

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Sequelae of previous events

European CHESS project (n=541)

Mean number of target joints

18-30	1.04
31-40	1.16
41-50	1.25
51-60	1.43
61+	0.89

Interactions

- stenting for coronary stenosis in haemophilia
  - dual antiplatelet treatment?
- type 2 diabetes in haemophilia
  - what type of exercise?
- malignancies in virus-infected patients
  - surgical approaches?
  - effects of radio- en chemotherapy?

Conclusion

- ageing haemophilia patients offer complex medical questions
- ageing patients differ by cohort and location
- the number of older patients grows rapidly
- targeted research needed
  - gerontologists
  - epidemiologists
  - patients

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