Registers in Denmark

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Use of routine care data in research

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- Clinical register at SDC
  (Electronic Medical Records, EMR)

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- Register-based projects at
  Steno Diabetes Center

Reasons to do register-based studies

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- Low participation rate in observational studies

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(SDC electronic patient records)

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- Note: Intervals between visits depend on patients' status

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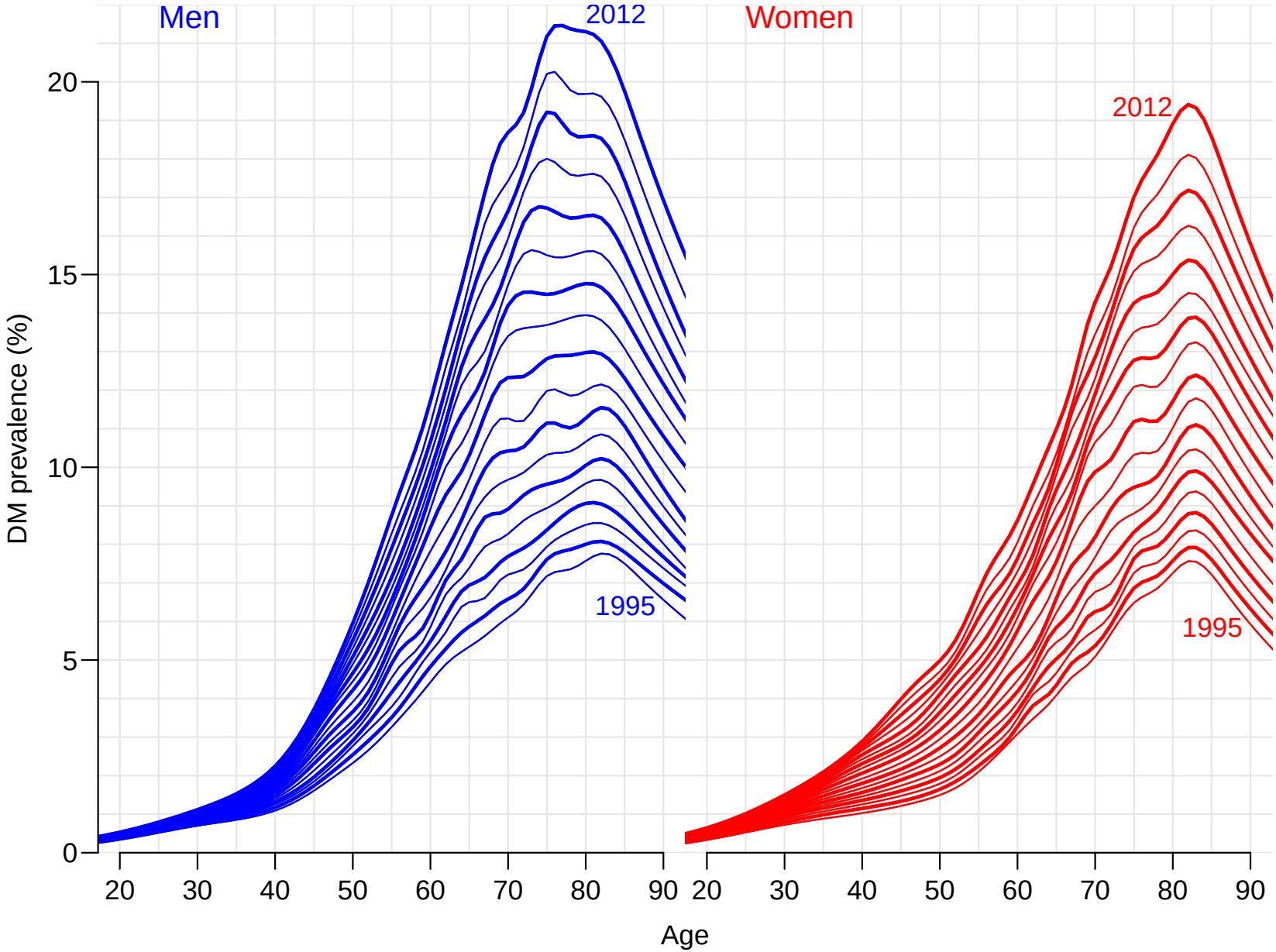
  - Mortality of DM patients
  - Relative mortality of DM patients (SMR)

NDR 1995-2012: Prevalence[1]



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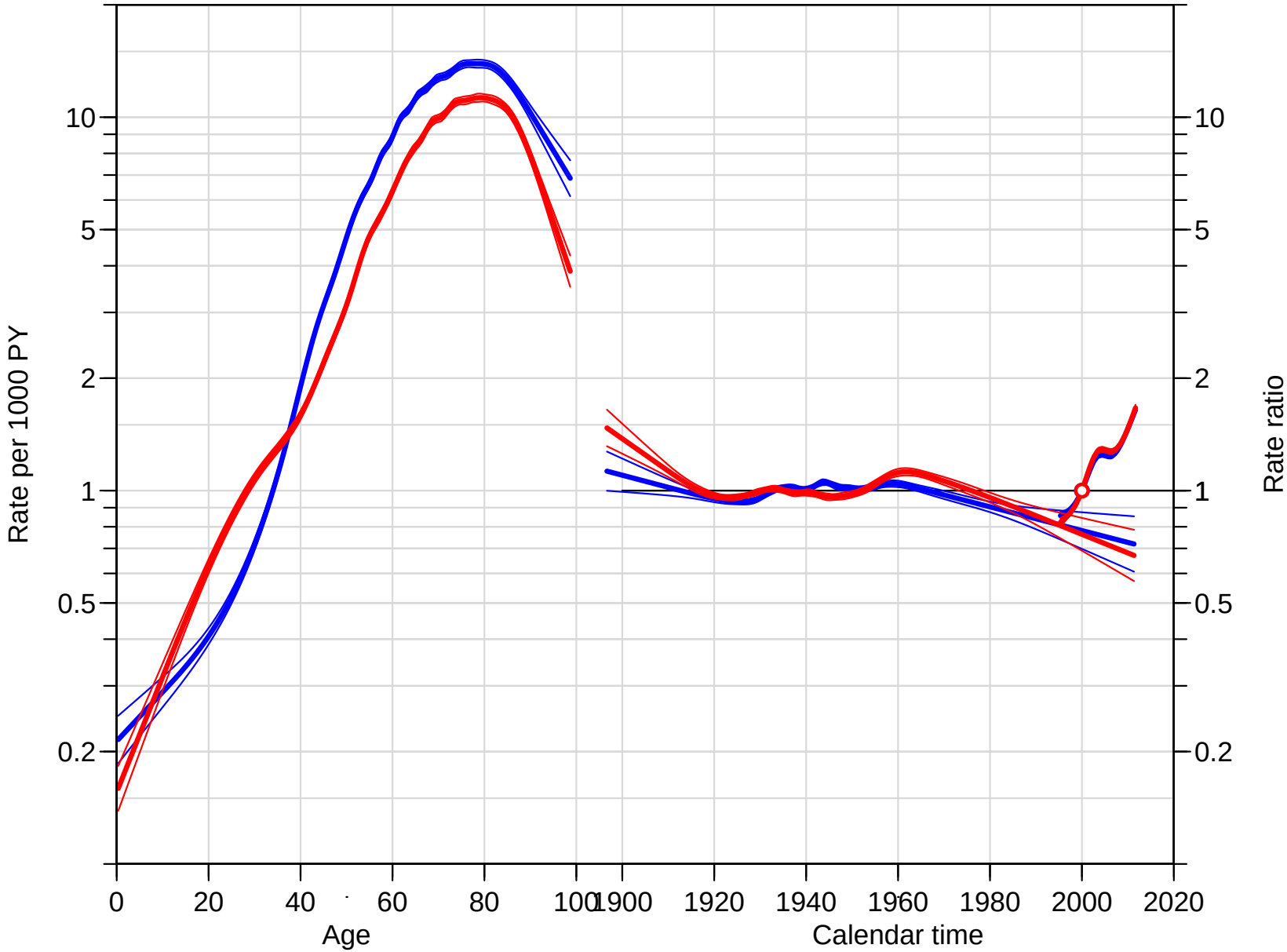
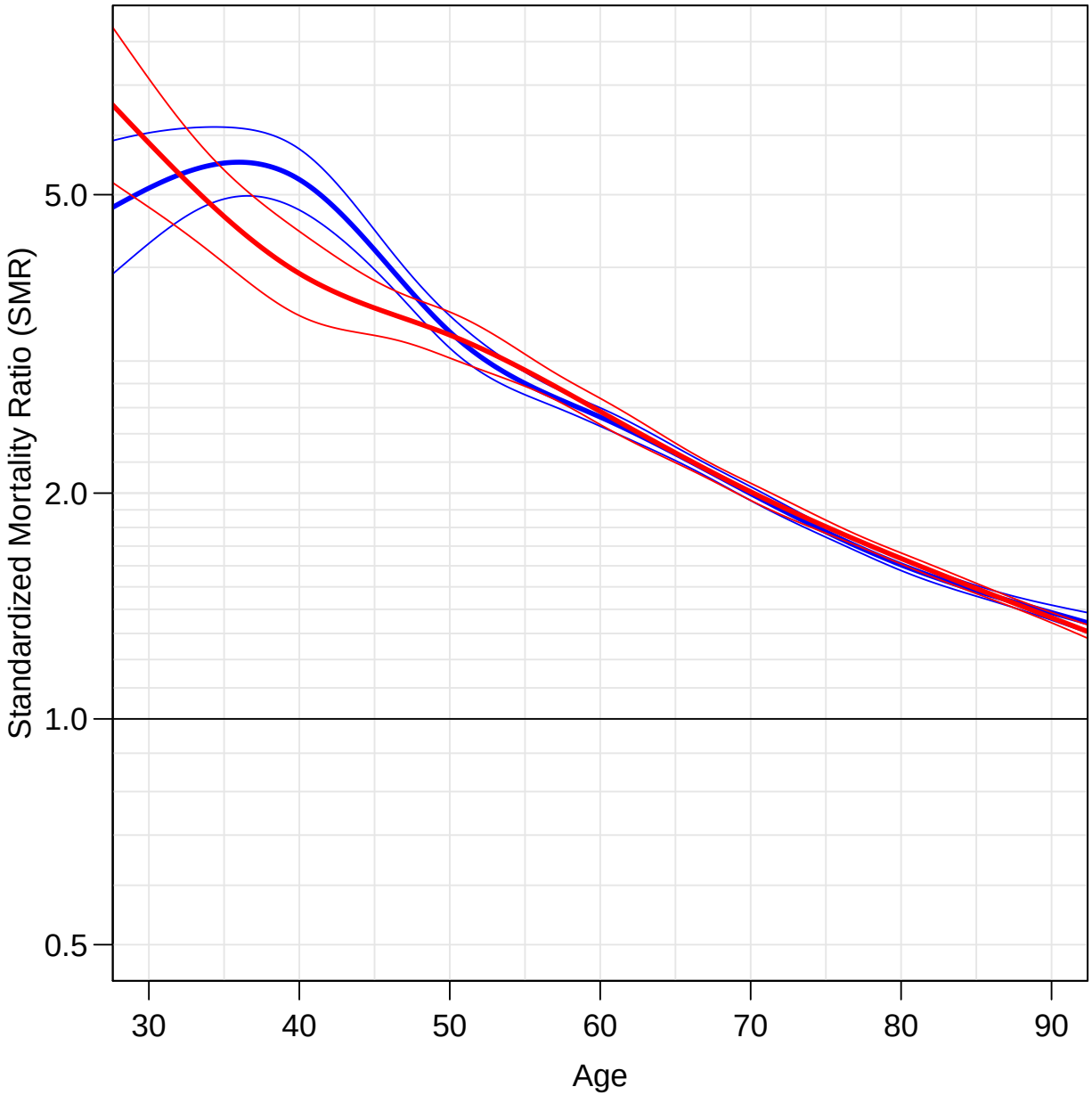


NDR 1995-2012: SMR[1]



Mortality among SDC T1 & T2 patients

Patients followed 1 Jan 2002 to 31 Dec 2010 [2, 3]

	T1		T2	
	Men	Women	Men	Women
No. patients	2,614	2,207	3,423	2,421
Annual decrease (%):				
Mortality	6.6	4.8	5.5	3.3
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So also in SDC patients mortality has been declining **more** than in the general population.

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- How do rates depend on clinical parameters?
- How is long-term outcome dependent on clinical status?

SDC:
T1DM patients with kidney compliations

- G. Andresdottir, M. L. Jensen, B. Carstensen, H. H. Parving, K. Rossing, T. W. Hansen, and P. Rossing: **Improved Survival and Renal Prognosis of Patients With Type 2 Diabetes and Nephropathy With Improved Control of Risk Factors**
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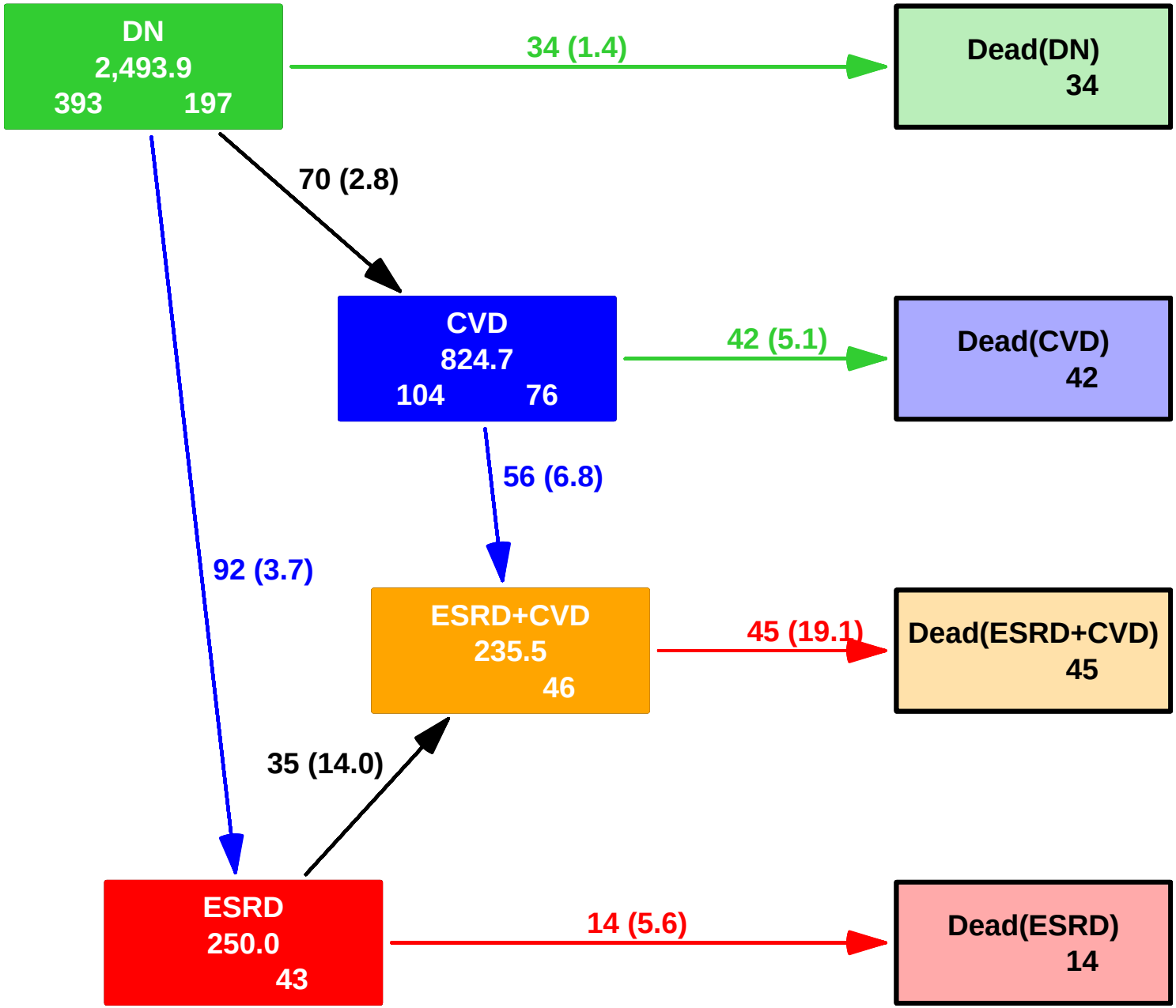
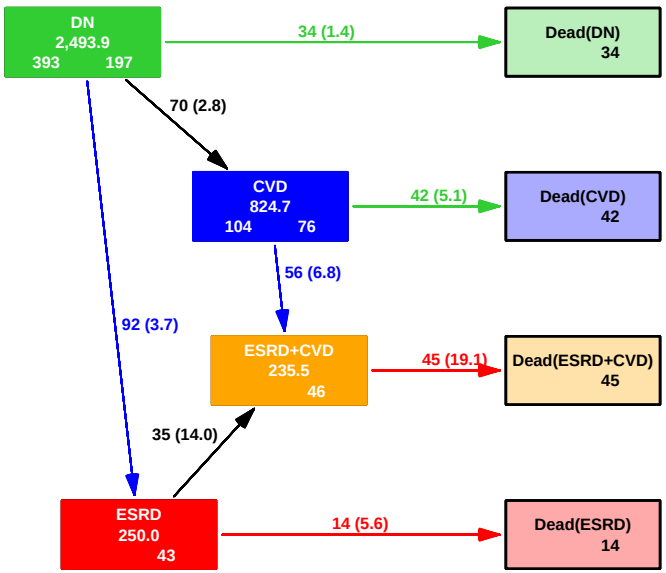
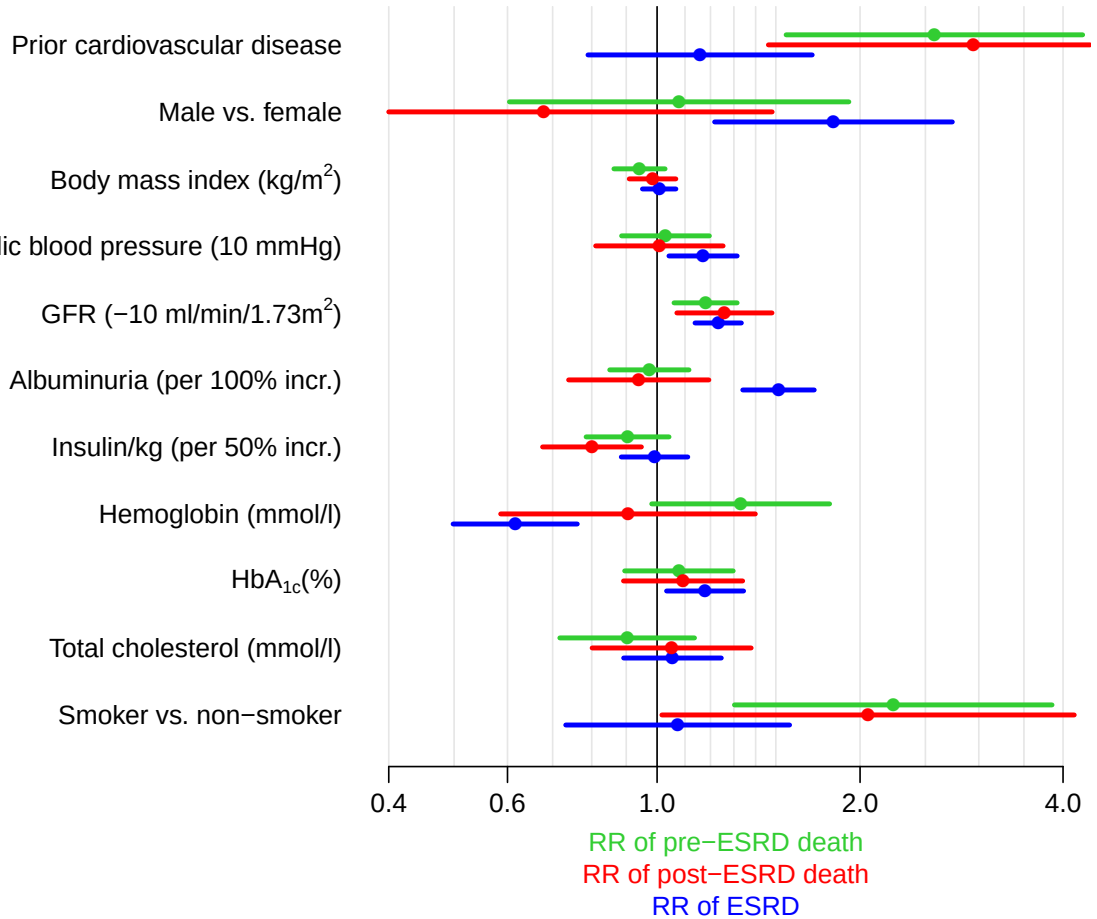
- Clinical parameters at date of DN (baseline)

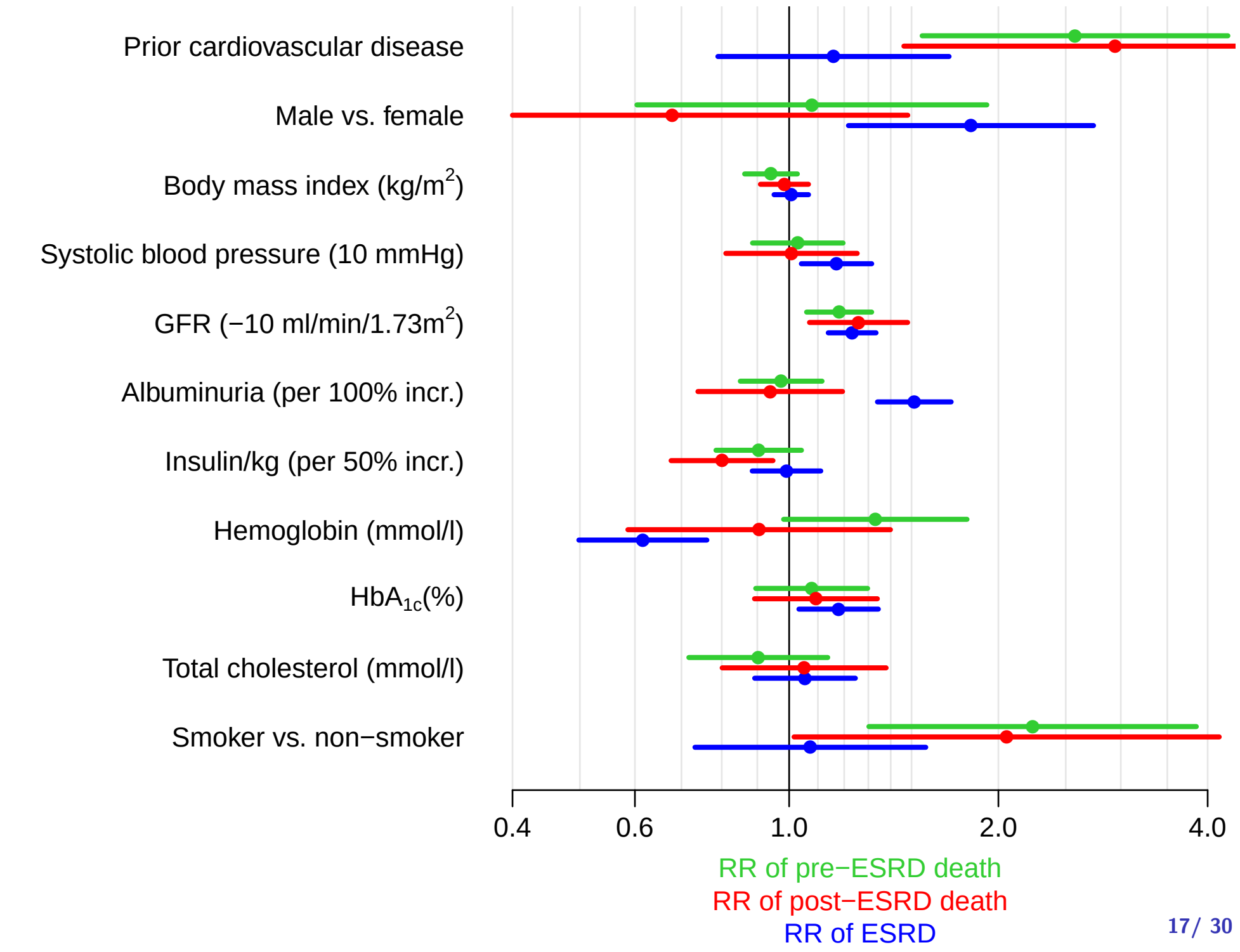
T1DM patients with kidney compliations



Covariate effects

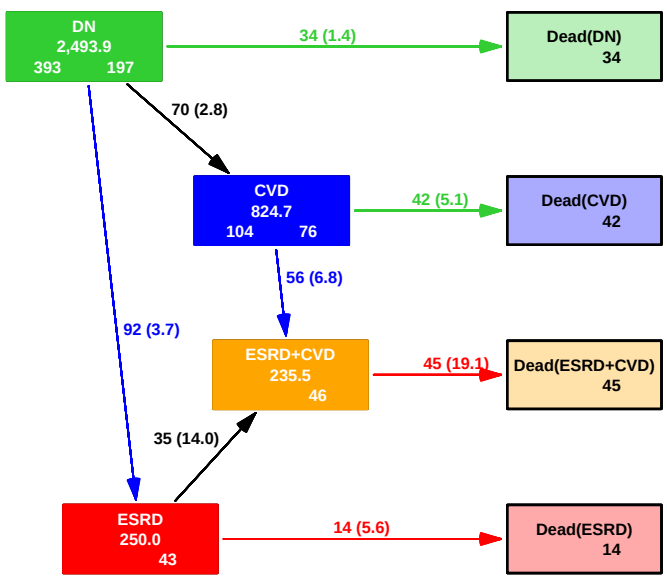


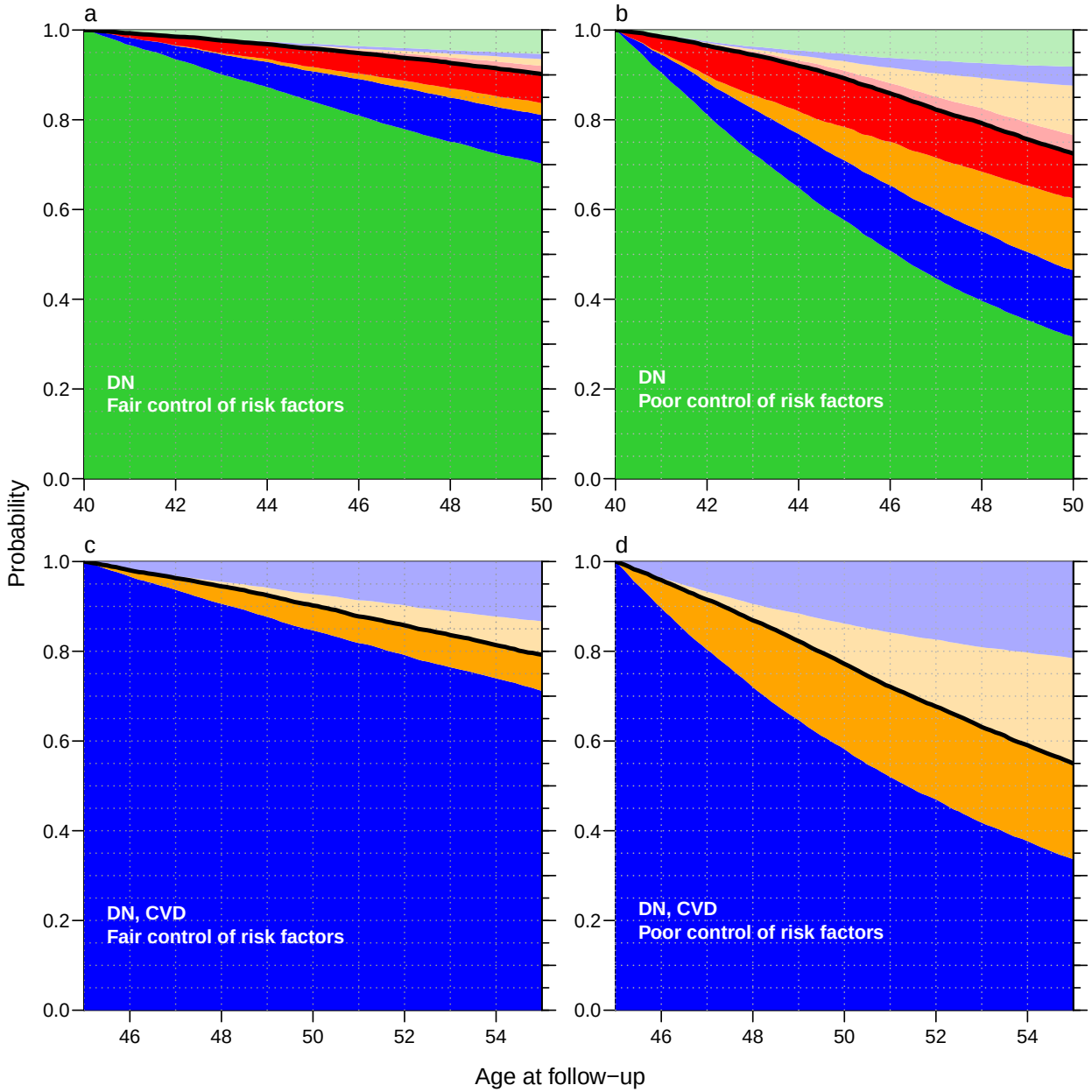



Prior cardiovascular disease
Male vs. female
Body mass index (kg/m^2)
Systolic blood pressure (10 mmHg)
GFR (−10 ml/min/1.73m^2)
Albuminuria (per 100% incr.)
Insulin/kg (per 50% incr.)
Hemoglobin (mmol/l)
HbA$_{1c}$(%)
Total cholesterol (mmol/l)
Smoker vs. non−smoker
0.4
0.6
1.0
2.0
4.0
RR of pre−ESRD death
RR of post−ESRD death
RR of ESRD

Example patients

Regulation	Fair	Poor
Sex	Man	Man
Age	40/45	40/45
Time since DN	5	5
Diabetes duration	25	25
HbA_{1c}	7.5	9.0
Systolic blood pr.	130	150
Total cholesterol	4.5	5.5
Albumin	300	1000
Smoking	never, <3	4–20, 20+
BMI	22	22
GFR	70	70
Hemoglobin	8	8
Insulin dose per kg	0.75	0.75


DN
2,493.9
393 197
34 (1.4)
Dead(DN)
34
70 (2.8)
CVD
824.7
104 76
42 (5.1)
Dead(CVD)
42
56 (6.8)
92 (3.7)
ESRD+CVD
235.5
46
45 (19.1)
Dead(ESRD+CVD)
45
35 (14.0)
ESRD
250.0
43
14 (5.6)
Dead(ESRD)
14


a
b
c
d
Probability
DN
Fair control of risk factors
DN
Poor control of risk factors
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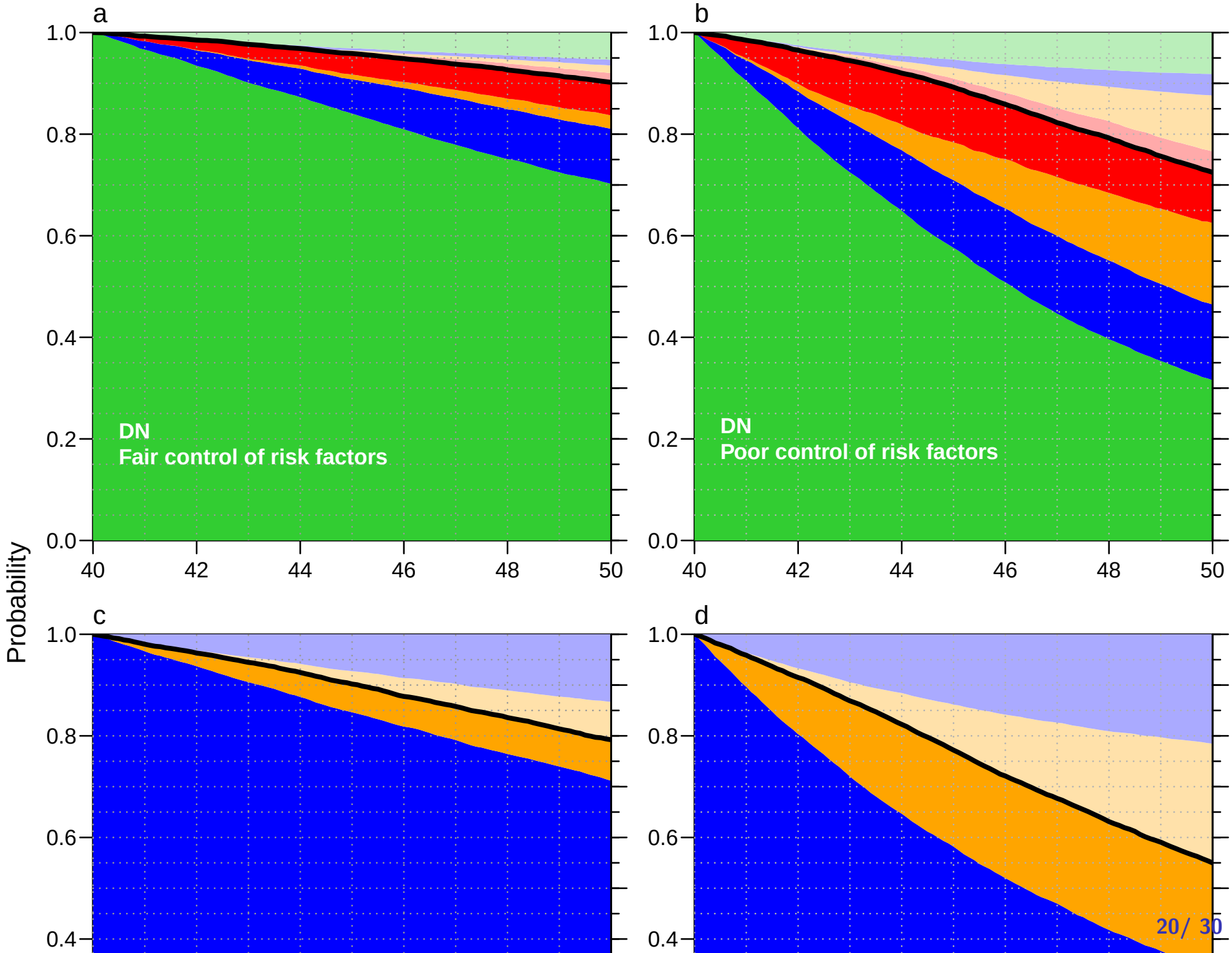
Age at follow−up


a
b
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Probability
1.0
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0.6
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0.0
40
42
44
46
48
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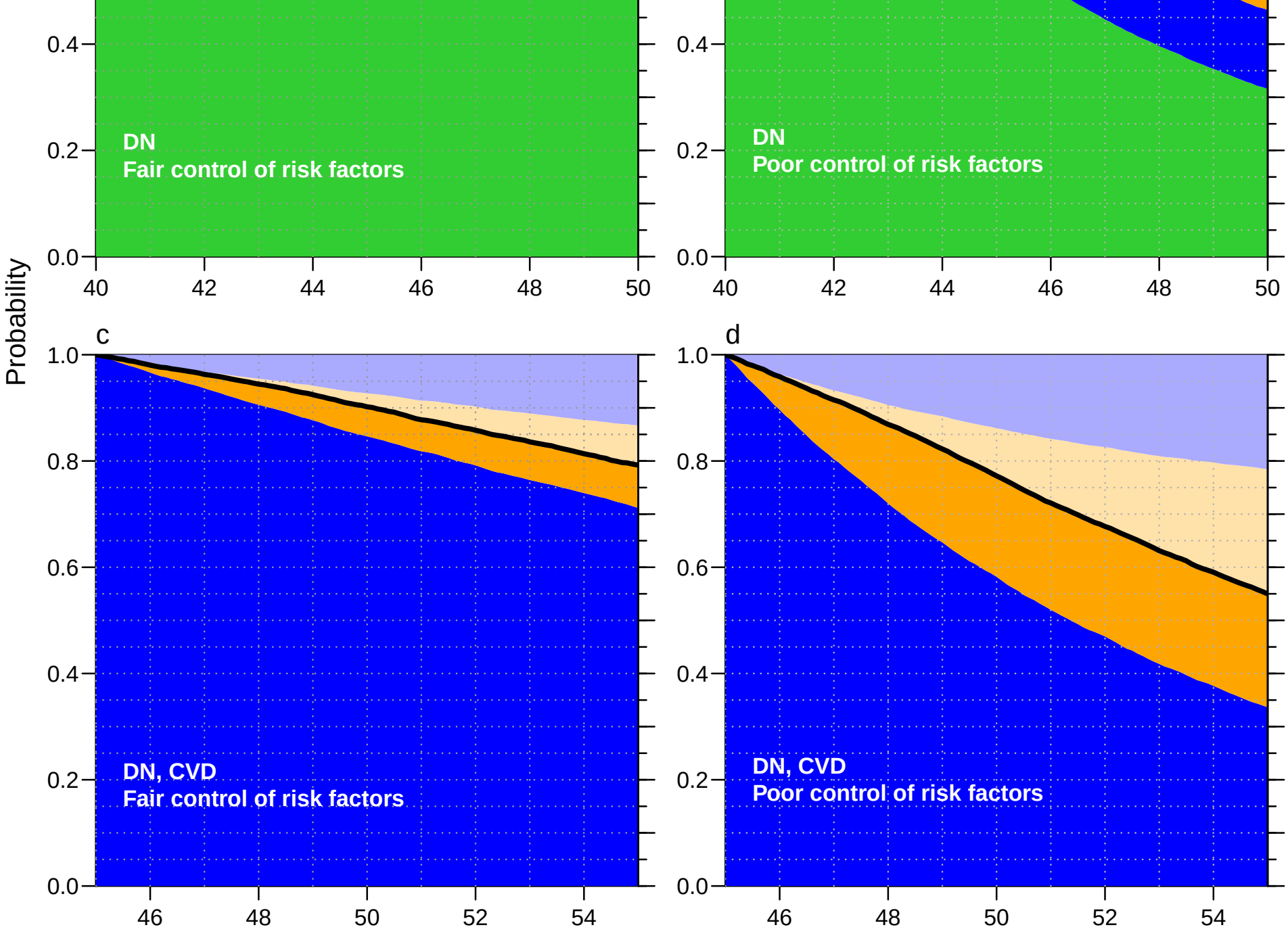
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52
54

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- ...but it is possible with the SDC EPR.

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  - *i.e.* are there factors that influence rates that are not mediated through the measured clinical variables?

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  - improvement in overall patient prognosis mediated through improvement in clinical variables?

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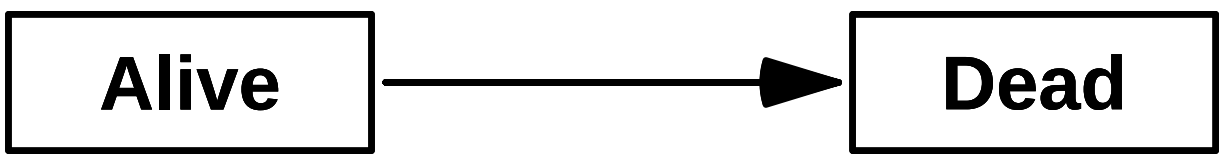

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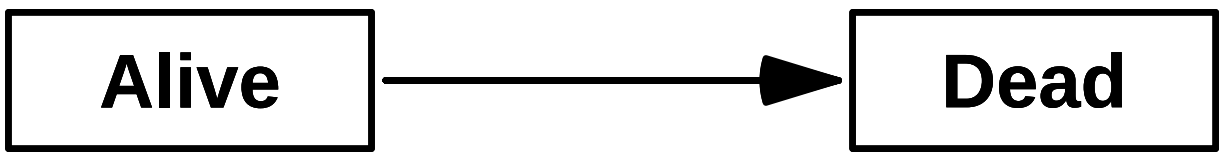

Population level prediction

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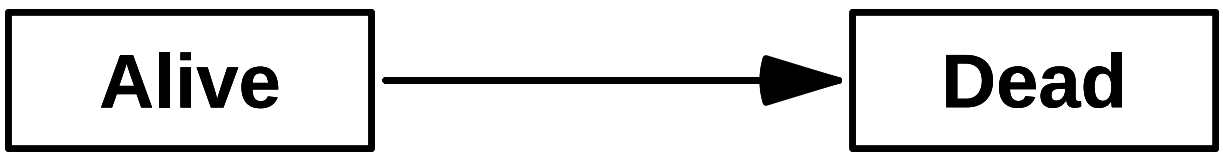
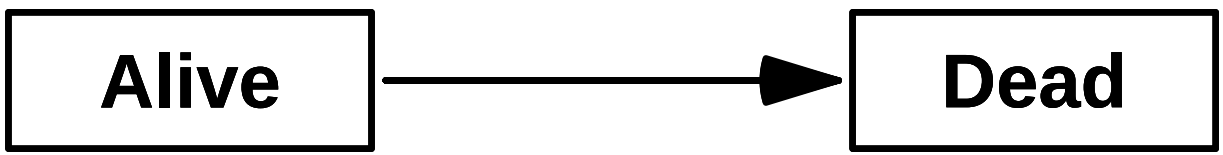
- as the expected length of life
- **under the assumption** that rates are as seen in the population

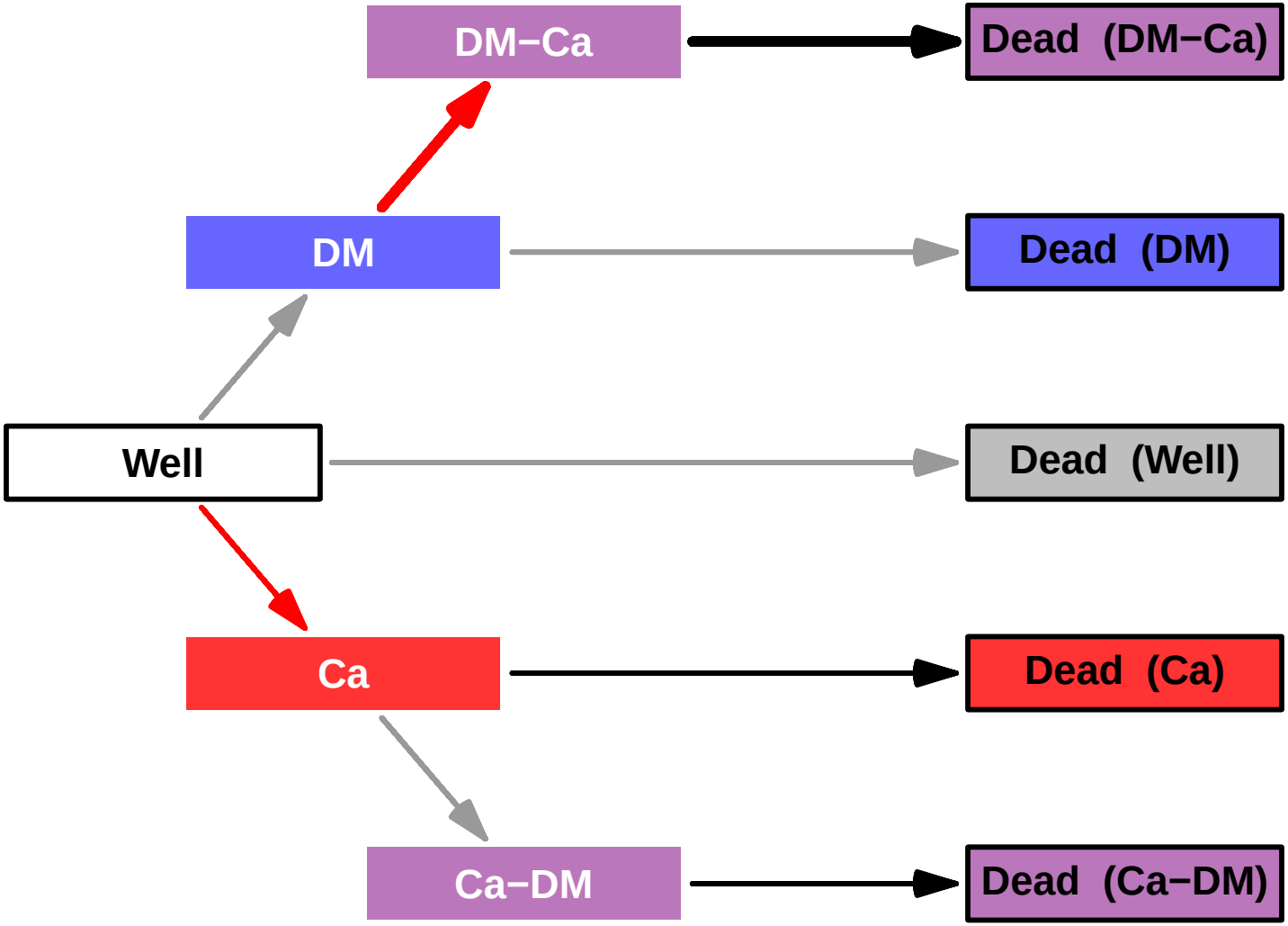


Population level prediction

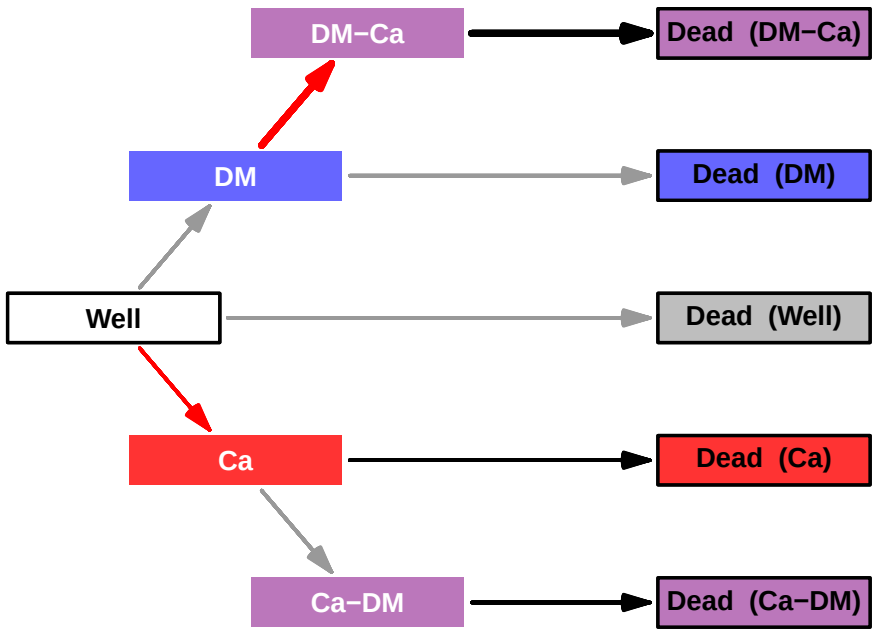
- Demographers compute the life expectancy in a population
- as the expected length of life
- **under the assumption** that rates are as seen in the population
- at a certain point in time:



Population level prediction



Population burden of DM & Cancer

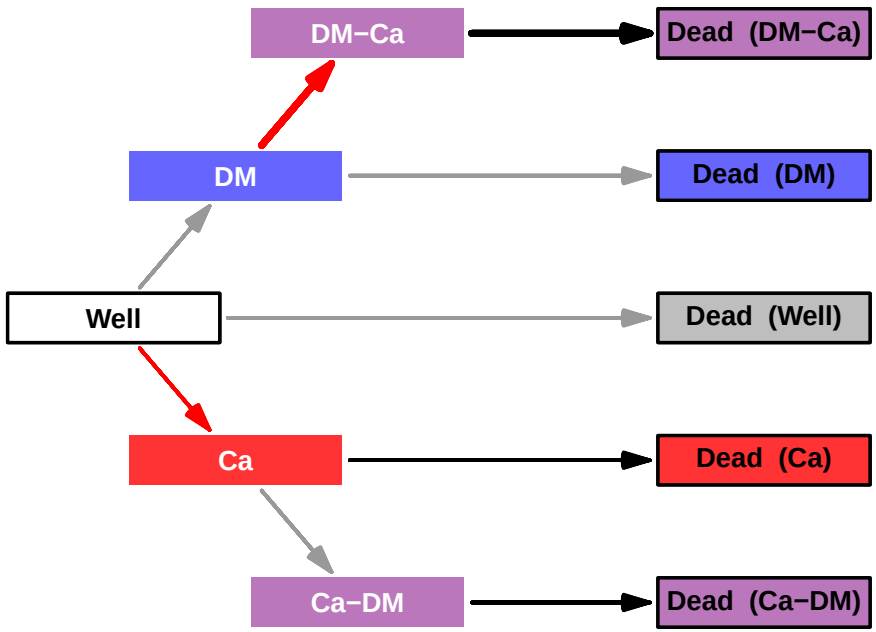


Population burden of DM & Cancer

- How many people get cancer?

How are the persons distributed between states at a given point in life?

Depends on **all** the transition rates

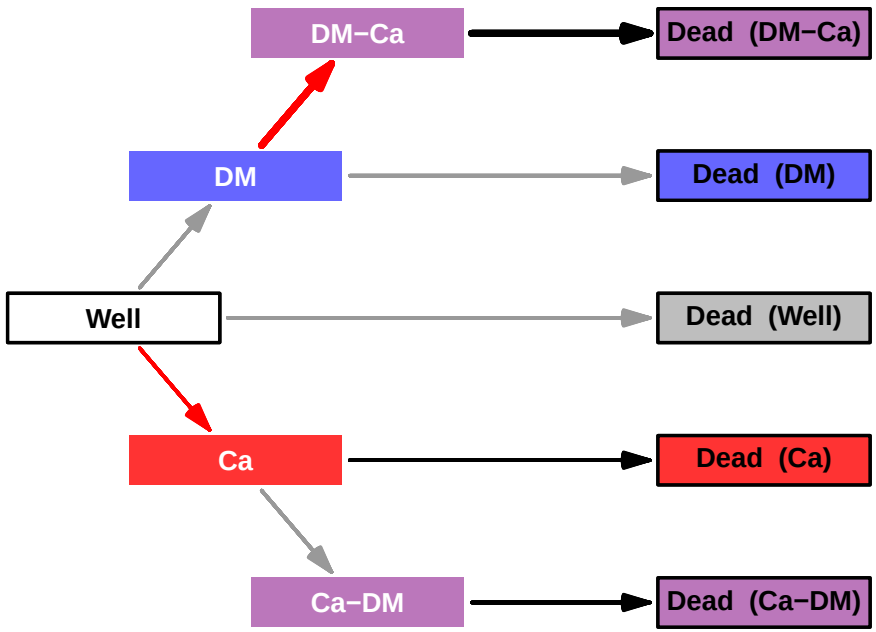


Population burden of DM & Cancer

- How many people get cancer?
- How many people get diabetes?

How are the persons distributed between states at a given point in life?

Depends on **all** the transition rates

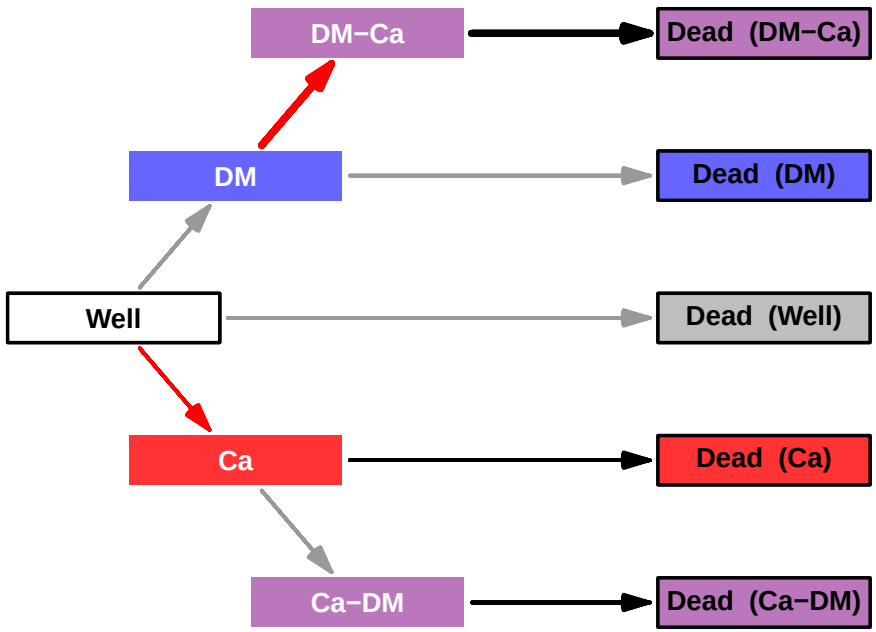


Population burden of DM & Cancer

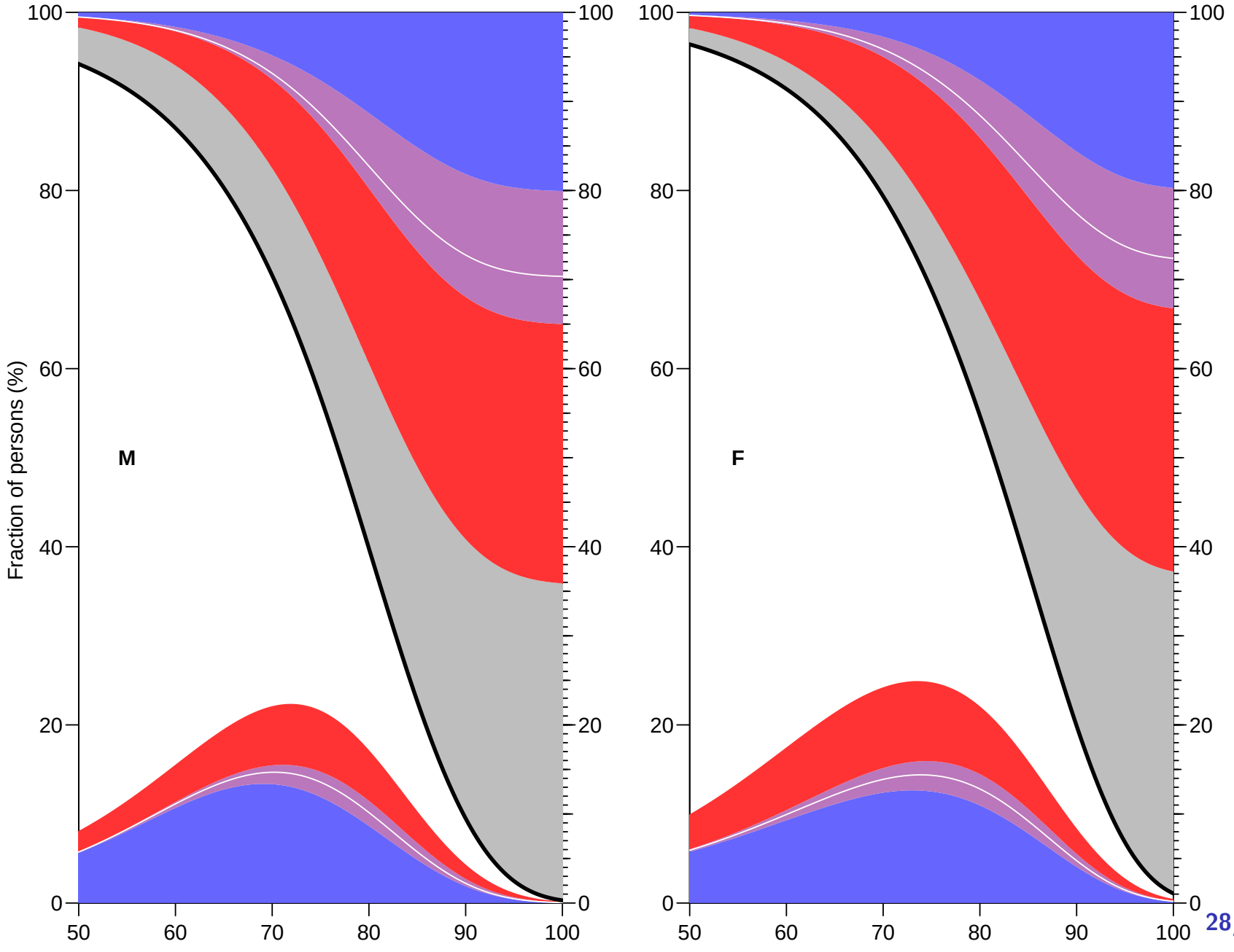
- How many people get cancer?
- How many people get diabetes?
- How many people get both DM and cancer?

How are the persons distributed between states at a given point in life?

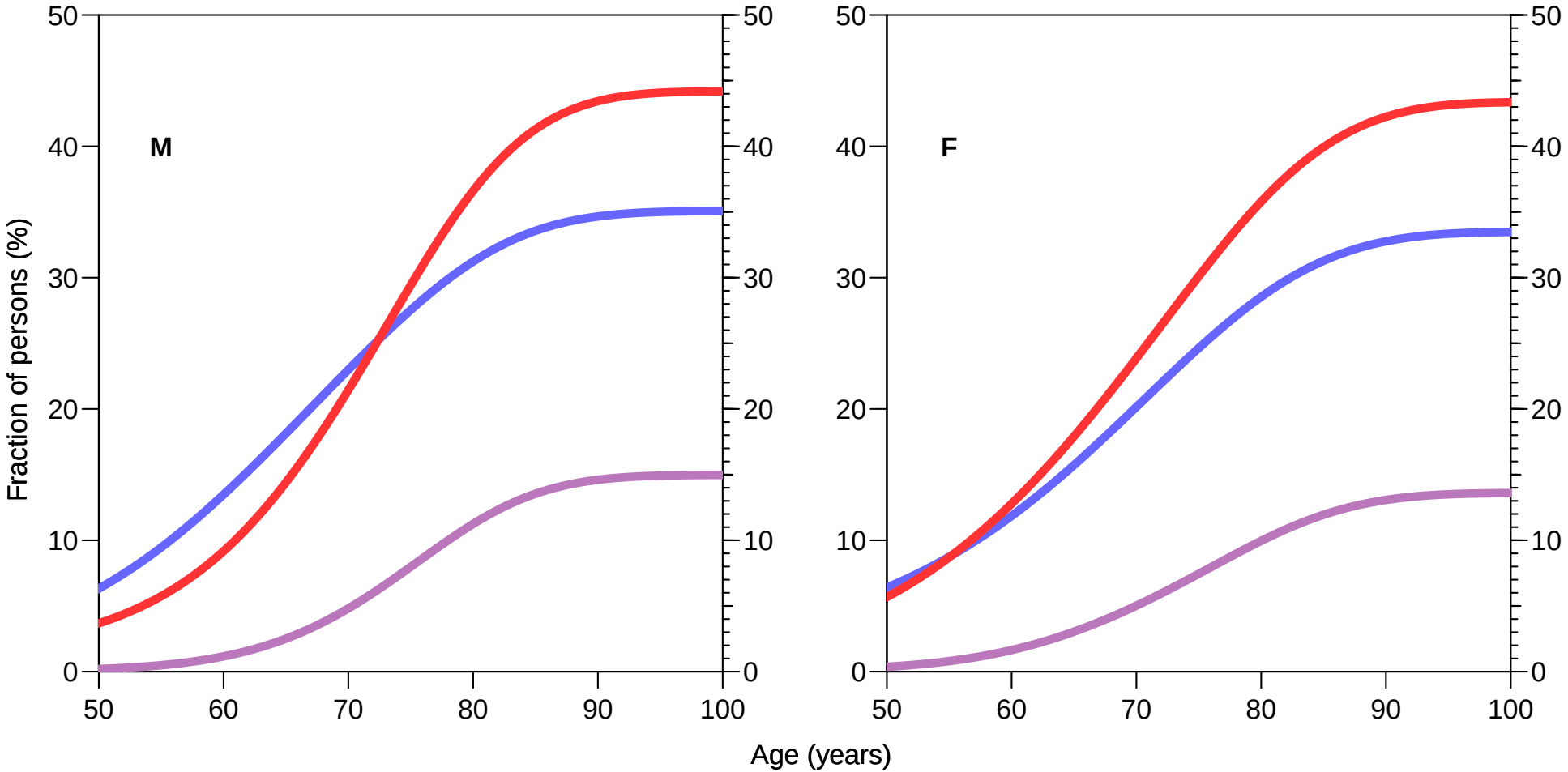
Depends on **all** the transition rates



Population burden of DM & Cancer



How many get DM/Cancer before age a



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