

## Background

### Years of life lost in the context of electronic health records

Years of life lost (YLL) is a measure that summarizes the global impact of disease in a population in terms of premature deaths. The YLL is classically estimated using age of death as a starting point. In the electronic health records, as the measure of mortality is only available for short periods (e.g., until end of study follow-up), alternative estimations using the age at diagnosis as a starting point and extrapolation on survival on longer follow-up than the one observed can be computed<sup>1</sup>.

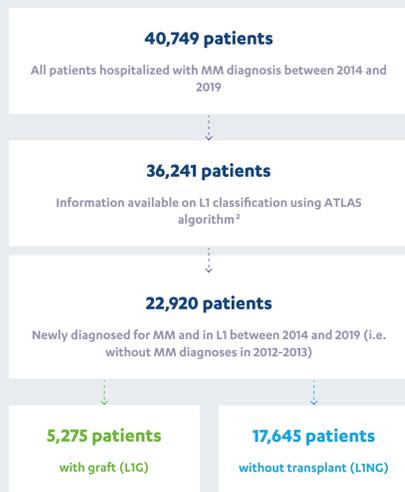
## Objectives

To estimate the number of YLL among incident patients with multiple myeloma (MM)

## Design / Settings

Data was available from a retrospective observational cohort study of MM patients identified through the French NHI databases (SNDS).

Patients with graft (LIG) were available with a median follow-up duration of 2.1 years.



## Conclusion

### Study result:

- The mean number of YLL for MM patients in L1 varies between 9.2 and 13.5 years according to the method of estimation.

- The mean number of YLL is higher in the transplant group (13.6–24.8 years) with more variability between methods. The extrapolations of survival in this group are less reliable because as the patients are younger, the extrapolation may have had more impact (less death observed, longer follow-up to complete). This highlights the importance of using several methods to estimate the YLL in electronic health records.

### General conclusion on YLL calculation:

- Method 1 is widely used in the literature due to its simplicity and allows comparisons with other reference studies. However, it applies only to deceased patients and tends to overestimate YLL.

- Other methods are available and feasible on electronic health records<sup>1</sup>, these methods were selected because of the simplicity of implementation.

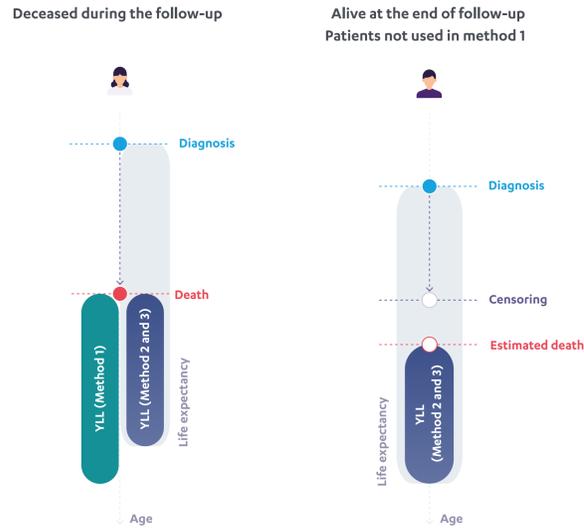
- In electronic health records and in general with heavily censored data, alternative estimations relying on hypotheses on survival among diseased patients will provide more accurate estimations by considering the distribution of ages at diagnosis for a given disease.



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## Methods

### Calculation of YLL for patients



### Aggregated life tables (INSEE) by year, age and sex

	Life expectancy LE (ref pop age,sex)	Death probability within the year
Method 1 <sup>1</sup>	✓	✗
Method 2 <sup>2</sup>	✓	✗
Method 3 <sup>3</sup>	✓	✓

	Age of diagnosis	Age of death in case of death	Age at the end of follow-up
Method 1 <sup>1</sup>	✗	✓	✗
Method 2 <sup>2</sup>	✓	✓	✓
Method 3 <sup>3</sup>	✓	✓	✓

### SNDS individual data set

### Details of implementation

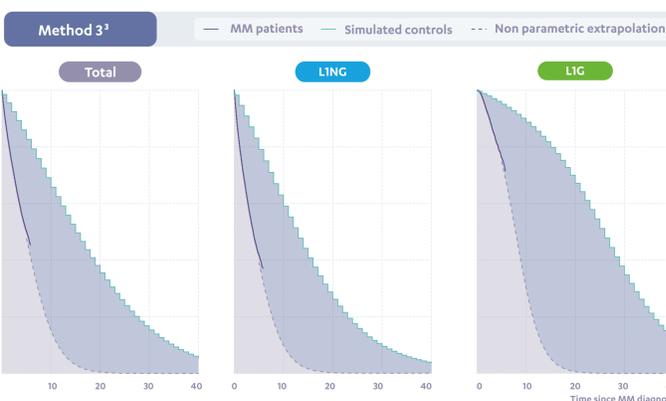
	Extrapolation for the survival curve*	Formula for extrapolation	Formula for YLL
Method 1 <sup>1</sup>	None (non-deceased patients not used)		$YLL = \sum_{i \text{ Death}} LE_{age \text{ death}}$
Method 2 <sup>2</sup>	Parametric Weibull model adjusted on age at diagnosis and sex for MM patients and LE estimation for patients in general population.	$S_{MM \text{ patients}}(t) = \exp(-(\lambda t)^\alpha)$ with $\log(\lambda) = \beta_0 + \beta_1 \text{age} + \beta_2 \text{sex} + \sigma \epsilon$ and $\epsilon \sim G(0, 1)$ $LE_{age \text{ diag}}(MM \text{ patients}_{s_1 age_1, sex_1}) = \int_{age \text{ diag}}^{95} S_{MM \text{ patients}}(u age_1, sex_1) du$	$YLL = \sum_i (LE_{age \text{ diag}}(MM \text{ patients}_{s_1 age_1, sex_1}) - LE(\text{ref pop} age_1, sex_1))$
Method 3 <sup>3</sup>	Linear extrapolation of a logit-transformed curve of the survival ratio between a simulated control population from life tables with similar age and sex as the MM study population.	$S_{MM \text{ patients}}(t) = S_{\text{similar ref pop}}(t) * \frac{\exp(\alpha_0 + \alpha_1(t))}{1 + \exp(\alpha_0 + \alpha_1(t))}$ with $\text{logit}(\frac{S_{MM \text{ patients}}(t)}{S_{\text{similar ref pop}}(t)}) = \alpha_0 + \alpha_1(t) + \sigma N(t)$ and $N(t) \sim N(0, 1)$ $LE_{age \text{ diag}}(MM \text{ patients}) = \int_0^{+\infty} S_{MM \text{ patients}}(u) du$	$YLL = LE_{age \text{ diag}}(MM \text{ patients}) - LE_{age}(\text{Similar ref pop})$

## Results

	Total	LIG	LING
Gender (% of men)	51.79% 11,871 patients	56.45% 2,978 patients	50.40% 8,893 patients
Mean age at diagnosis	69.93 ±12.20 years	58.57 ±8.08 years	73.32 ±11.13 years
Mean duration of follow-up	2.25 ±1.61 years	2.87 ±1.54 years	2.06 ±1.58 years
Death during follow-up	32.27% 7,396 patients	13.54% 714 patients	37.87% 6,682 patients
Mean age at death	75.95 ±11.07 years	61.12 ±7.85 years	77.53 ±10.15 years



	Total	LIG	LING
Patients used in calculation	22,920 patients	5,275 patients	17,645 patients
LE reference population	18.0 years	26.5 years	15.4 years
MM patients LE	8.7 years	12.9 years	6.6 years
YLL	9.2 years	13.6 years	8.8 years



	Total	LIG	LING
Patients used in calculation	22,920 patients	5,275 patients	17,645 patients
LE reference population	17.1 years	25.5 years	14.6 years
MM patients LE	5.3 years	7.9 years	4.4 years
YLL	11.8 years	17.6 years	10.2 years

(1) Andersen, Per Krageh. « Life Years Lost among Patients with a given Disease ». Statistics in Medicine 36, no 22 (2017): 3573-82. <https://doi.org/10.1002/sim.7357>.  
 (2) Plana-Ripoll, Oleguer, Vladimir Canudas-Romo, Nanna Wey, Thomas M. Laursen, John J. McGrath, et Per Krageh Andersen. « Lillies: An R Package for the Estimation of Excess Life Years Lost among Patients with a given Disease or Condition ». PLOS ONE 15, no 3 (2020): e0228073. <https://doi.org/10.1371/journal.pone.0228073>.  
 (3) Chu, Po-Ching, Jung-Der Wang, Jing-Shiang Hwang, et Yu-Yin Chang. « Estimation of Life Expectancy and the Expected Years of Life Lost in Patients with Major Cancers: Extrapolation of Survival Curves under High-Censored Rates ». Value in Health 11, no 7 (2008): 1102-9. <https://doi.org/10.1111/j.1524-4733.2008.00350.x>.