Long Abstract (2-4 pages)

Introduction:

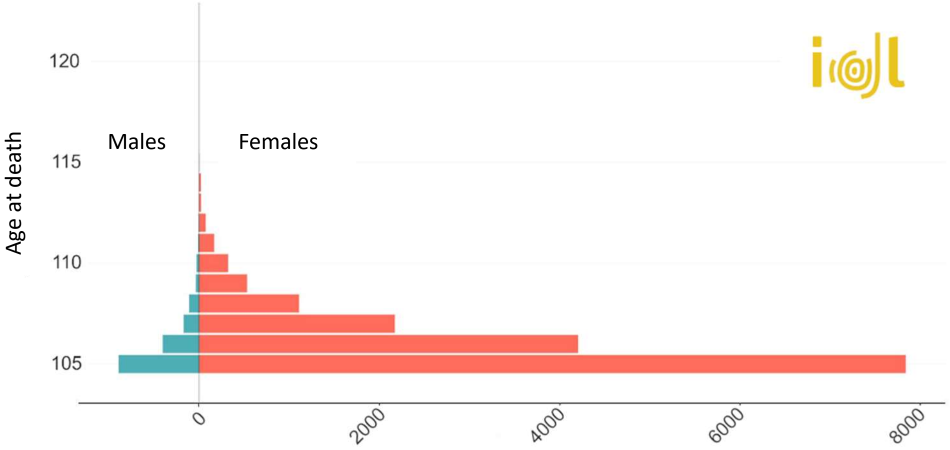
The International Database on Longevity (IDL) is the result of a cooperative project that began in the 2000s, involving various international research institutes and researchers. The first website was published in 2010 by the Max Planck Institute for Demographic Research (MPIDR), which maintained the IDL until 2019. Since then, the responsibility for its development and maintenance was transferred to the French Institute for Demographic Studies (INED). In recent years it has undergone significant changes and updates. INED has not only taken over the IDL but also updated the database and migrated it to a new website in 2022.

The IDL is accessible at www.supercentenarians.org and managed by INED's Datalab in collaboration with the INED research unit "Mortality, Health, and Epidemiology" (MSE) under the supervision of its Director, Carlo G. Camarda. This database offers valuable source for researchers investigating the limits of human longevity and exploring mortality risks within the oldest age groups[1, 2].

1. The current state of the International Database on Longevity (IDL)

The International Database on Longevity (IDL) is a database containing individual data on 18,959 semi-supercentenarians (deceased at ages 105-109) and supercentenarians (deceased over age 110) from thirteen different countries. The 13 countries are: Austria, Belgium, Canada – Quebec, England & Wales, Denmark, Finland, France, Germany, Japan, Norway, Spain, Sweden, United States. For the same countries, with the exception of Finland, Sweden, Spain and Japan, IDL collects data on semi-supercentenarians.

For the 18,959 individuals currently in the database, the information provided (determined in accordance with the legislation of the various countries) is: gender, date of birth, date of death, completed age in years, region of birth and region of death, as well as the type of validation carried out on a systematic basis. To protect privacy, all data in the IDL are anonymized, ensuring the confidentiality of individuals. IDL is a database that fits in with the open science policy, since researchers may access it for free after completing a simple registration process and accepting the terms of use.



Graph 1. Age pyramid of deceased included in the IDL

Data collection for the IDL is a collaborative effort that involves country specialists from (or in relation with) national institutes of statistics. Data sources must to be exhaustive. These specialists follow standardized IDL guidelines for accurate data validation. While the validation procedure may vary across countries, these variations are clearly explained in the metadata provided for each country. Regardless of the differences, the validation process typically relies on early life documents, including birth certificates and census records. Records that do not meet the specified age threshold or fail to provide a satisfactory determination are excluded. For records pertaining to individuals aged 110 and older, validation is a mandatory step. In contrast, given the larger number of individuals aged 105-109, only random samples of semi-supercentenarians may go through the validation process.

2. Challenges with Data Collection

Over time, the IDL has encountered a notable reduction in the number of countries contributing to its dataset. While in March 2004 it included 17 countries (13 European countries, Japan, Australia, United States and Canada)[3], currently it has only thirteen. This reduction is primarily attributed to certain countries' reluctance to disclose individual records due to legal protections and privacy concerns.

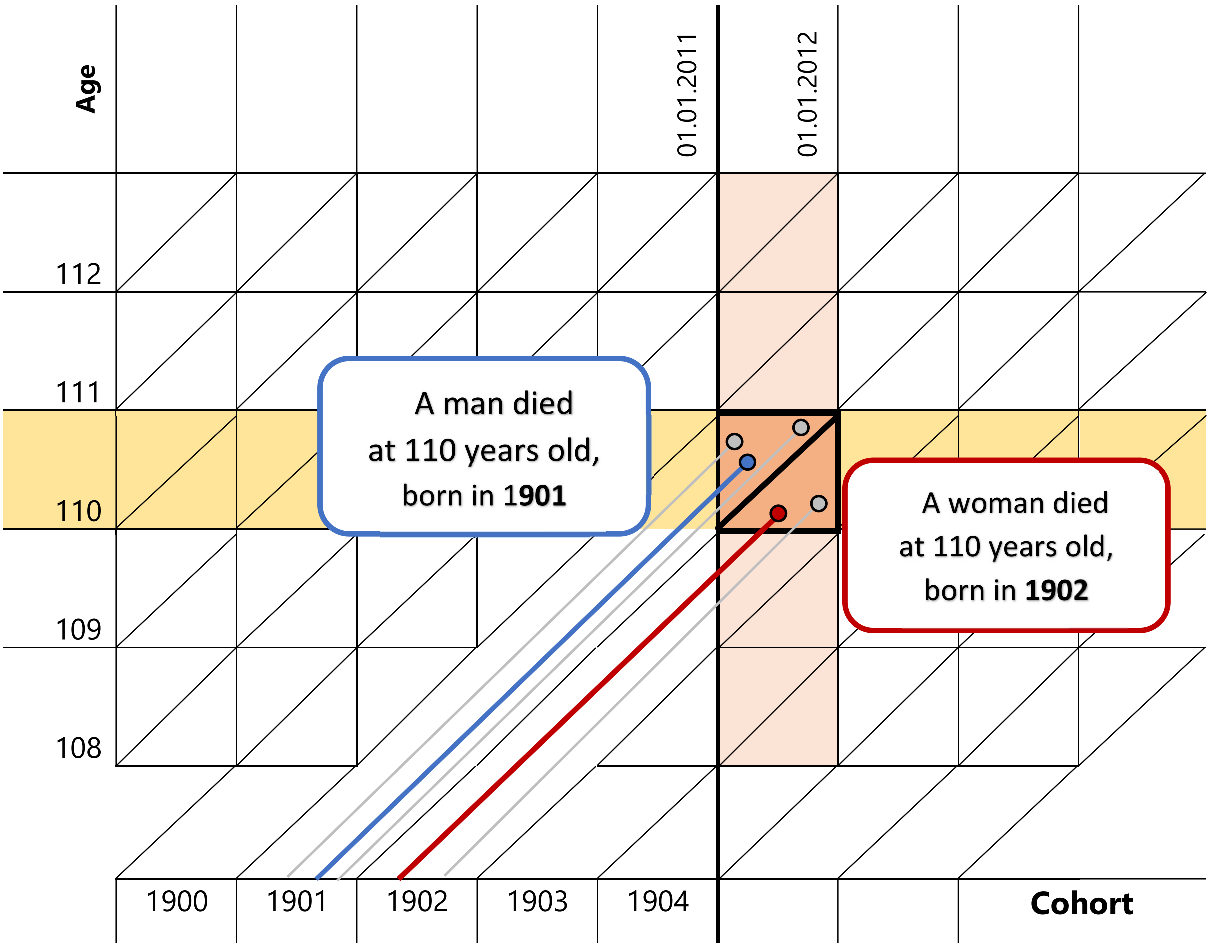
Article 27 of the General Data Protection Regulation (GDPR), which is in force in European Union clarifies that the regulation (protection of individual data) does not apply to personal data of deceased individuals. It allows member states to establish their own rules regarding the processing of personal data of deceased persons.

In the case of France, the rules regarding the processing of personal data of deceased individuals are outlined in the Law for a Digital Republic of October 7, 2016, specifically in Article 63 (which amends the Data Protection Act). This law allows disclosure of these data, unless otherwise explicitly asked by the deceased person’s heirs. Individuals can indeed leave to their heirs, directives regarding the processing of their personal data after their death. It appears that heirs may also have the possibility to object to the processing of the deceased person's personal data. However, in the absence of opposition or advance directives from the individual, the processing of this data is generally considered outside the scope of the GDPR and the Data Protection Act. It's worth noting that there may be exceptions, such as protected secrets that prevent the disclosure and dissemination of information.

Given this context, it would be interesting to investigate what are the national legislation that applies in each country, in Europe and beyond, and that led to withdrawal of data from the IDL. However, such an investigation is quite challenging because we would likely need to face language barriers. In order to continue to provide data even for the countries that do not want to disclose data at the individual level anymore, we propose to aggregate data at the very detailed level – triangles of Lexis.

3. Alternative Solution – method

The suggested solution, aggregating data in Lexis triangles, addresses the concerns of countries not willing to share individual data, and at the same time facilitates international comparisons and research in the field of longevity and mortality. Despite a critical loss of information, the proposed approach continues to rely on individually validated data (as it should be already validated by the national institutes of statistics (NIS), which supply IDL with basic data). Individuals of the same age and that belongs to the same cohort (born on the same year) form a triangle. It may be upper or lower triangles, that together include all the deceased persons of the same age during a calendar year.



Graph 2. Example of extract from the Lexis diagram

4. Conclusions

The significant advantage of this type of aggregation is that it still enables to do both period and cohort analyses. The primary goal is to promote greater participation from various countries in the IDL project, thus making broader international comparisons possible. The IDL, with its high-quality, age-validated individual-level data and its commitment to minimizing age-ascertainment bias, stands as a unique and valuable source of information on extreme human longevity. It is well worth the effort to address its limitations and expand its coverage.

References:

1. Ouellette, N., Meslé, F., Vallin, J., & Robine, J.-M. (2021). Supercentenarians and Semi-supercentenarians in France. In Exceptional Lifespans (pp. 105–123). Springer, Cham.
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