



Heales
HEALTHY LIFE EXTENSION
SOCIETY

Big Data for Longevity Research

Ravda, Bulgaria (virtual), September 10, 2022

Didier Coeurnelle, co-chair Heales

Facts about Longevity

Death toll

120,000

Maria, Vladimir, Wei, Satya, Fatima Jing and John.

Death toll

European countries: 90 %

World: 70 %

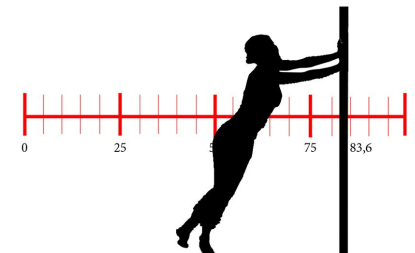
Poorest countries: 50 %

Only three big categories of diseases due to aging

- Cardiovascular diseases
- Cancers
- Neurodegenerative diseases

But

- Infectious diseases (flu, tuberculosis, covid...)
- Falls
- ...



However (healthy) maximal lifespan is NOT going up lastly

Yesterday

- Gain of 20 years in more 2000 years
- Maximum 122 years since 1997

Today

- Oldest person in the world 118
- Oldest man in the world 112



What I think ...

It is very probably possible to find
a treatment against aging within 15 to 30 years

But

Complicated and expensive

Reasons to be pessimistic
for the next months
(and even years)

Decrease of Life Expectancy

-0.92 year in 2020 and -0.72 year in 2021

Results

The increase in the number of deaths during the pandemic had a substantial impact on the global life expectancy. After 69 years of uninterrupted increase from 1950 to 2019, the global life expectancy is estimated here to have declined by -0.92 years between 2019 and 2020 and by another 0.72 years between 2020 and 2021 (for both sexes, Figure 2). In 2021, the global life expectancy is estimated to have dropped below its 2013 level.

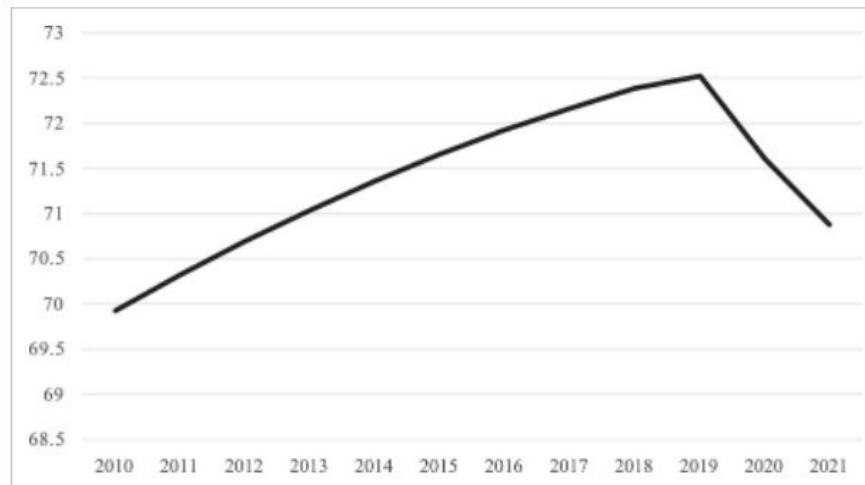


FIGURE 2

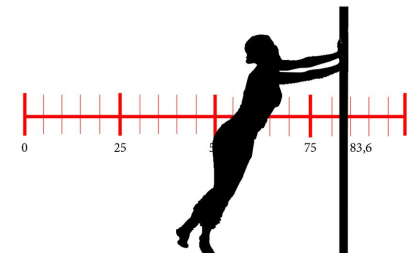
[Open in figure viewer](#) | [PowerPoint](#)

Global life expectancy, 2010–2021 (both sexes, in years)

SOURCE: 2010–2019, United Nations (2019); 2010–2021, author's calculations (see the Appendix for details)

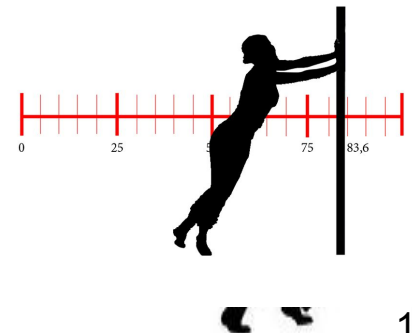
Global and National Declines in Life Expectancy: An End-of-2021 Assessment. Patrick Heuvelin.

<https://onlinelibrary.wiley.com/doi/10.1111/padr.12477>



(Fragile) reasons to be optimistic

- We learned to work online
- We are more interconnected than ever
- Life has never been so precious culturally, especially concerning old people



Facts about Digital Health

Big Data and Health : Where is the information?

Scientific Literature

Your smartphone and the Tech Giants
(social networks)

Administrations and Medical Institutions
(medical doctors, hospitals, health sector, social security)

30 % of Big Data is Health Big Data



400,000 Healthcare Apps in the App Stores



0 public space to share Health Data for all



Trash in / Trash out

- Veracity
- Problems related to Commercial Software / Companies
- Anonymization (better for privacy)
- Pseudonymisation (better for sharing data)
- Negative results must be available



We have enough Health Data in the World

To know which clinical tests should be start immediately

To know which existing drugs have (very probably)
positive longevity effects

To know which existing drugs have (very probably)
negative longevity effects



Big Data Situation in Europe

European institutions

Communication from the Commission to the European Parliament

«Those actions will be funded through the EU Health programme 200, DEP and Horizon Europe programmes with the goal by **2025** to ensure that : **citizens** from all the Member States **are able to share their health data with healthcare providers and authorities of their choice.**»



Belgium

My Health

nl fr de en

Other government information and services: www.belgium.be

Myhealth

You are not logged in - Log in

NEWS

- 2021.07.15: [Overview of my COVID tests](#)
- 2021.07.08: [Test result and Certificate from a CTPC code](#)
- 2021.06.21: [Codes for free or paid PCR tests](#)
- 2021.06.16: [European COVID Digital Certificate](#)
- 2021.02.25: [Vaccination data](#)

Free or paid PCR tests
For residents in Belgium
All information available here

What is MyHealth.be?
MyHealth is an online health portal, also known as "Personal Health Viewer". Through this central gateway you gain insight into various personal data about your health and about health in general.

COVID 19 - Personal data
Information about requesting free or paid PCR tests
This section gives you access to the visualisation of your personal data* and to different possible actions related to the COVID-19

COVID 19 - Information
In this section you will find information about the Coronavirus.
General information: [info-coronavirus.be](#)
Vaccination COVID19

Source : <https://www.myhealth.belgium.be/>

Health Data Sciensano

About healthdata.be About Sciensano Management bodies News Documents

healthdata.be
data we care for

Projects Services Processes

Healthdata's mission is to facilitate the data exchange between healthcare professionals and researchers to increase public health knowledge in Belgium.

I'm looking for...

Useful links

- Data collection definitions
- Statistics
- Clinical Building Blocks

Inventory
An inventory creates a handy overview of the known registries in Belgium dealing

Data collection
We provide a technical interface with encrypted data, which is 100% reliable

Reporting
Healthdata.be supports the registry administrators providing them access to

Source : <https://healthdata.sciensano.be>

Belgium : in practice

My Online Medical File

Datum ▼	Type
15/05/2019 (11:28)	Consultatieverslag
14/05/2019 (11:39)	Resultaat
14/05/2019 (09:09)	Patiënt notitie
14/05/2019 (00:00)	Laboresultaten
13/05/2019 (11:12)	Consultatieverslag
12/05/2019 (00:00)	Laboresultaten
11/05/2019 (13:08)	Consultatieverslag
11/05/2019 (00:00)	Laboresultaten
11/05/2019 (00:00)	Laboresultaten
11/05/2019 (00:00)	Laboresultaten

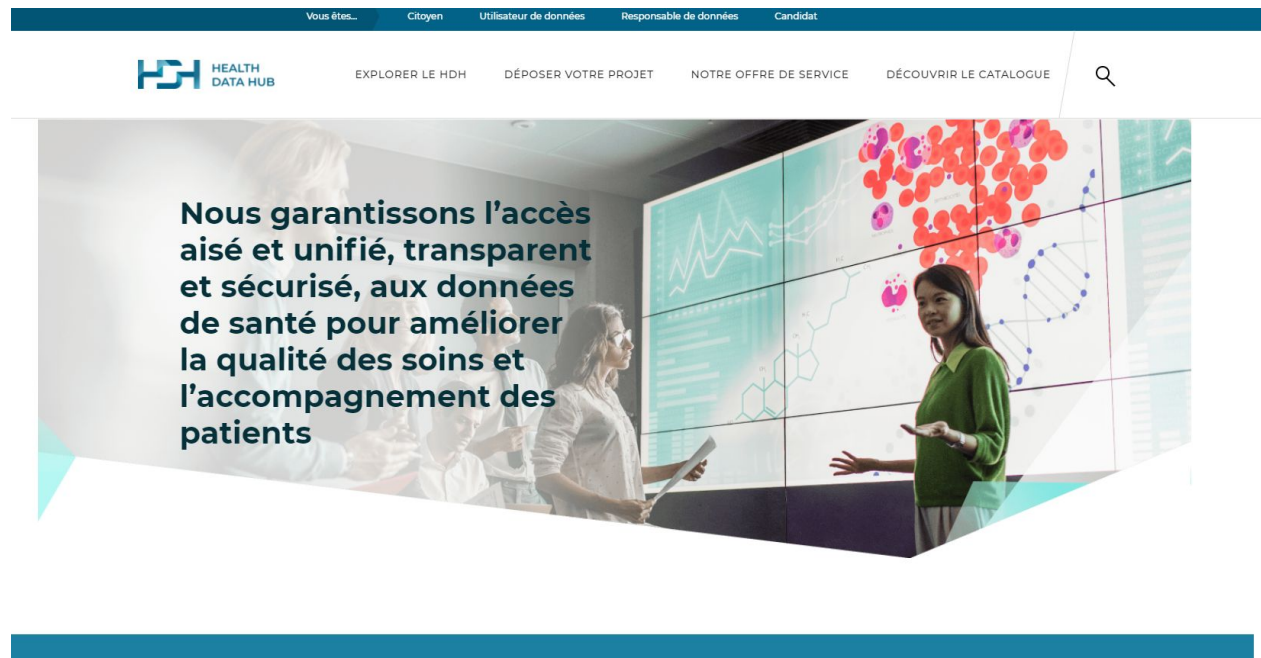
1 2 3 4 5 ... >>

Profiel	Service	Site	Toegang	Toegang patiënt	Tracering
Arts	endocrinologie/hormonenleer	CHUSP	Beheren	Toegang niet geopend door het ziekenhuis	Tracering
Arts	Radiologie	CHUSP	Beheren	Toegang niet geopend door het ziekenhuis	Tracering
Arts	-	CHUSP	Beheren	Toegang niet geopend door het ziekenhuis	Tracering
Arts	-	CHUSP	Beheren	Toegang niet geopend door het ziekenhuis	Tracering
Arts	endocrinologie/hormonenleer	CHUSP	Beheren	Toegang niet geopend door het ziekenhuis	Tracering
Arts	-	CHUSP	Beheren	Toegang niet geopend door het ziekenhuis	Tracering
Arts	Intensive care	CHUSP	Beheren	Toegang niet geopend door het ziekenhuis	Tracering
Arts	-	CHUSP	Beheren	Toegang niet geopend door het ziekenhuis	Tracering
Arts	-	CHUSP	Beheren	Toegang niet geopend door het ziekenhuis	Tracering
Arts	-	CHUSP	Beheren	Toegang niet geopend door het ziekenhuis	Tracering



France

Health Data Hub



“We ensure easy, unified, transparent and secure access to health data to improve the quality of care and support for patients”



France : in practice

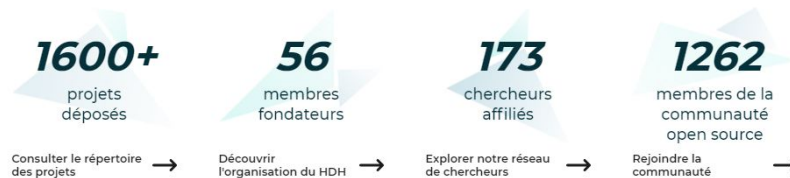
Pour vos projets d'accès aux données...

...retrouvez toutes les informations ici !

Vous souhaitez utiliser des données de santé dans le cadre d'un projet d'intérêt général ? Voici comment nous pouvons vous accompagner

Découvrir

Only 8 studies approved



Reminder: “remember to use the new scientific protocol format and to include the EDB SNDS in your file before submitting your authorization requests to CESREES and the CNIL” (details available on our Starter Kit page)

Finland

FinData

FINDATA
Social and Health Data Permit Authority

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News

The transition period related to requirements for secure operating environments extended by one year

31.08.2021

On September 1, 2021, the transition period related to secure operating environments audited in accordance with the Act on the Secondary Use of Health and Social Data will be extended until...

[Read more](#)

Requirements for secure operating environments will enter into force on 1 May 2021 – see our policies on applications and amendment applications

30.04.2021

The Sections of the Act on the Secondary Use of Health and Social Data on the requirements for a secure operating environment are applied in accordance with the transitional provisions of...

[Read more](#)

A Year in Review – Summary of Findata's operations in 2020

14.04.2021

Social and Health Data Permit Authority Findata's operation was initiated stepwise during the years 2019 and 2020. Take a look at the summary of Findata's first year as pictures below or load an...

[Read more](#)

- Social and Health Data Permit Authority FinData promotes secondary use of health and social data, facilitates data permit processing and improves data protection for individuals.

- Opting out and not opting in
- Access to be paid (but not very expansive)

Source : <https://findata.fi/en/>

The legal (& de facto)
situation in most countries
of the world can be
summarized as:

Obligation to share with private companies and public entities

In most countries, you are obliged to share health data:

- with private companies

and/or

- with public institutions

if you want to use their services



Some limited possibilities to use your data

In many countries, you can theoretically access your data

But

It is often difficult, partial, not reusable with other software than the original (proprietary) software.



Your data is private data used by others than you

In most countries, most of the data that can be used for research is

in law or in fact

private property (or property of public institutions that do not share it)



You are not allowed to share (most) of your data for science

In no country, you are allowed to be legally (sole) owner of your data and in fact, you are not allowed to share it with scientists.

Sharing would be unlawful : you are allowed to "binge-drinking" and smoke 50 cigarettes a day, but not to take small risks (or even no risk) to help science!

Even if you decide to do it, scientists will have problems if they use your data

Even if scientists decide to use, they will not be able to get an official publication



What can you do for a
few possible "open"
solutions

Legal and ethical aspects

- Constantly remind that most people are willing to share Health Data for scientific and medical goals
- And that GDPR (General Data Protection Regulation) and other rules are not above fundamental human rights, but must be compatible with them



Private Organizations

(International) Longevity Organizations



Private for profit companies
who are really ready to share health data

(be careful of nice words about "open", sharing...
without real sharing)

Support Work for Sharing Data of International Public Institutions

International Organizations: WHO



Support Work for Sharing Data of European Public Institutions

European Health Data Space



Support Work for Sharing Data of European Public Institutions

COM(2022) 197/2

Proposal for a regulation: May 3, 2022

Four great principles:

Interconnectivity of databases

"Altruist" Databases

No possible use for commercial goals.

Can be shared with scientists



New collective ways of sharing Data



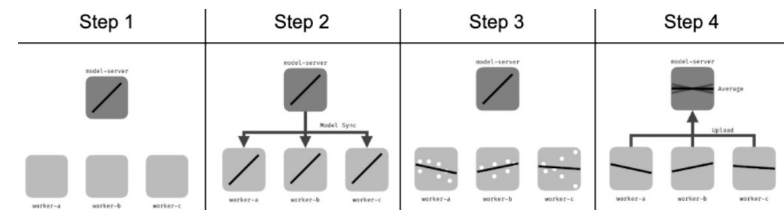
((Fictional Health Data))

Solid:

Data are stocked in a personal place. The ultimate goal of Solid is to allow users to have full control of their own data, including access control and storage location.

Federated learning:

Federated learning (also known as collaborative learning) is a machine learning technique that trains an algorithm across multiple decentralized edge devices or servers holding local data samples, without exchanging them.



A few legal (and ethical)
aspects

Your Health Data is sensitive

But less than

Your political life

Your Sex Life

Much of your private life

It would be less risky if:

The Health System is public

Health Data are not to be sold



Federal work in the US is Public Domain

A work of the United States government, as defined by the United States copyright law, is "a work prepared by an officer or employee" of the federal government "as part of that person's official duties. In general, under section 105 of the Copyright Act such works are **not entitled to domestic copyright protection** under U.S. law and are therefore in the public domain.



Patentleft / No Patent should be a general principle
at least for work made with public money

To facilitate:

Sharing of data

Publication of "negative" results

Research outside "patentable" fields



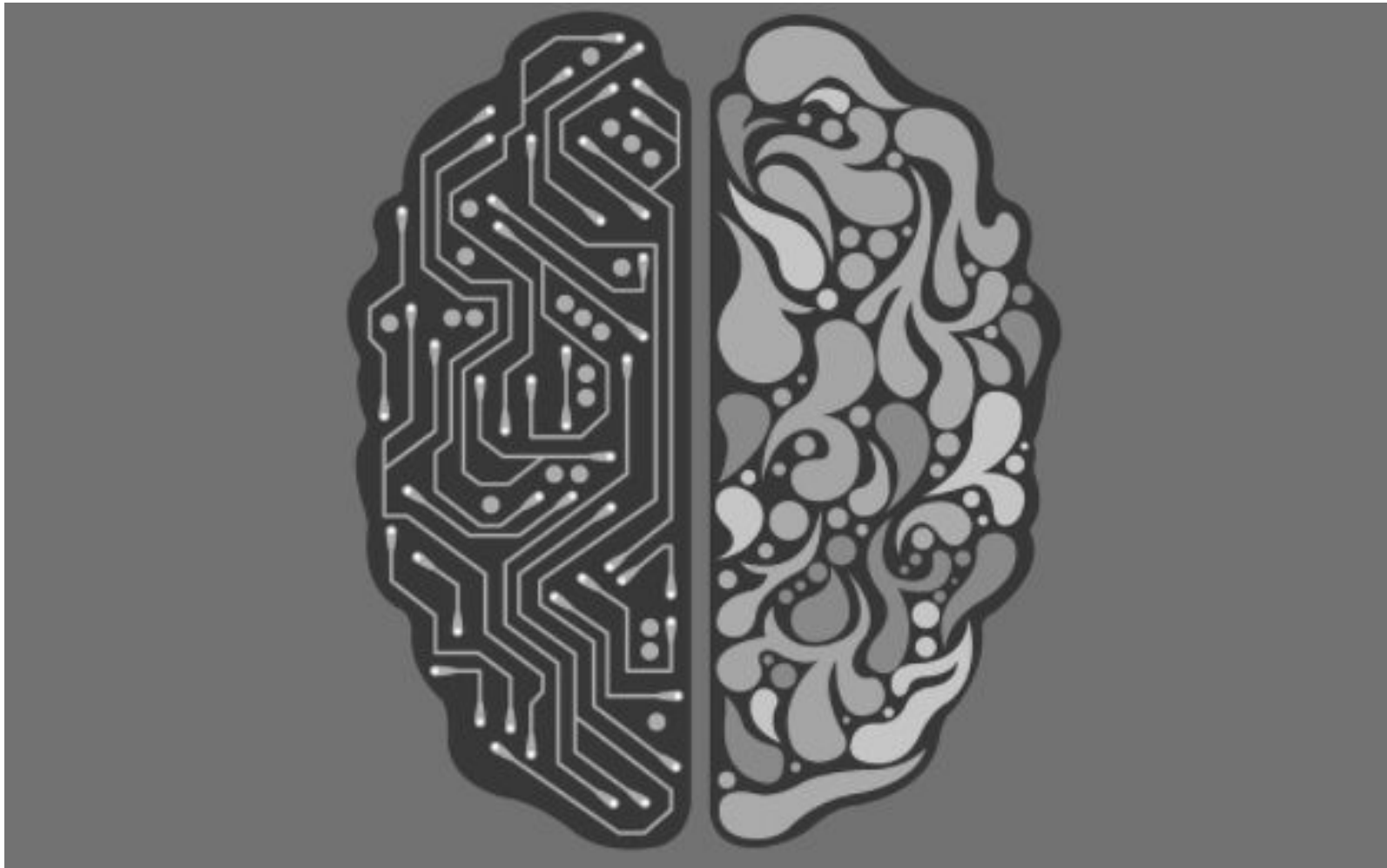
Do you own your Health Data or
is Health Data a Common Good?

If you own your Data, you have less solidarity

If Common Good, it is less dangerous
(nothing to sell, nothing to steal)



We should use A.I.



Beautiful progress especially DeepMind (unfolding proteins)
and InSilico Medicine

However

While Google translate and DeepL correct your mistakes

The best A.I. cannot (yet) considerably enhance your health

Conclusion

Today (before Covid) is the nicest day of the history of Humanity

Today is the most dangerous day of the history

There are more scientists more access to knowledge, more cooperation, more goodwill, more generosity and less violence(proportionally)

But also more bureaucracy, red tape (nor only for public institutions) than ever



Create a system
trusted by citizens
managed by a public institution or a non-profit organization
where by default (opt-out)
all health data
anonymized or pseudonymised
can be used for scientific research
and not for any other use

To start clinical tests

To enable everyone wishing it
to live a radically longer and healthier life.



Thank you!

Heales (Healthy Life Extension Society)
The ILA (International Longevity Alliance)

are among the organizations who are working resolutely in the
directions exposed.

Heales.org

Longevityalliance.org

Lifespan.io

Humanityplus.org

“Senectus vincenda est”

Subscribe to our newsletter : "The Death of Death"

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