

# Declaration of Sharing Health Data and Using AI for Healthy Longevity

Meeting in Brussels and Online. November 22 and 23, 2024.

## Introduction

The rapid advance of artificial intelligence (AI) has captured global attention, presenting both opportunities and risks. While these risks are undeniable, they can be mitigated if we prioritize the application of AI for the greater good, specifically in fostering healthy human resilience and longevity.

One crucial enabler for this vision is the sharing of health data for medical research, which is advancing under initiatives like the [European Health Data Space](#) (EHDS). However, the pace of progress is widely regarded as insufficient. Our collective ambition is to align with organizations and individuals committed to accelerating the responsible and effective health data sharing.

## Key Considerations

1. Availability of Health Data in the European Union
  - The majority of health data in the EU is already available online, creating a foundation for transformative research.
2. Progress of the European Health Data Space
  - The EHDS represents a significant step forward but is moving too slowly to address urgent medical research and longevity needs.

## Proposals for Action

### Empowering Patients and Data Accessibility

- Guarantee full portability and availability of all health data for patients, including their explicit right to share it for scientific purposes.

- Foster interoperability of data across all health and research domains, extending beyond classical medical records to encompass all digital health products.
- Enable broad consent and facilitate citizen / patient driven data sharing .

### Adopting Standards and Ethical Practices

- Ensure FAIR (findability, accessibility, interoperability, and reusability) data.
- Employ robust techniques for anonymization and pseudonymization to uphold patient privacy whilst advancing research.
- Encourage the establishment of altruistic databases where data is voluntarily shared for the common good.

### Leveraging AI for Data Management and Curation

- Use AI for curation, analysis, and management of large-scale health data to improve efficiency and accuracy.
- Establish a single point of contact (SPOC) in each EU country for scientists seeking to share or access health data.

## Key Steps for Implementation

1. Removing Bureaucratic Barriers
  - Simplify administrative processes to enable companies and public organizations to focus on developing treatments for aging and age-related diseases.
2. Commitment to Knowledge Sharing
  - Mandate that research funded with public money produces results that are openly accessible. Both negative and positive results, as well as pre-registered research plans, should be publicly available.
3. Once data is analyzed through AI, the development of genuine rejuvenation biotechnologies could occur through:
  - Virtual trials on digital twins of animals and humans.
  - Trials in vitro and on-a-chip
  - Blind trials on old mice or rats
  - Double-blind trials on well-informed elderly volunteers for real-world application.

## Conclusion

Since the beginning of the history of medicine, healthcare has been delivered through collective knowledge and individual experiences, despite often inaccurate beliefs and knowledge of the patient's condition. It is only relatively recently that patient data have become an important part of the field of knowledge, not only for the treatment of individuals themselves, but also for medical research.

One day, it could become self-evident that data useful for the right to health are a common good that we have to share with scientists.

One day, medical and research data on health and longevity could be accessible for all, so that research findings will enable citizens to live longer, more supportive and healthier lives.

May that day arrive as soon as possible!

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