



# IS DATA ALTRUISM STILL RELEVANT IN THE AGE OF THE EHDS?

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# INTRODUCTION

- Donation usually means organs, blood, or tissues.
- But what about donating our data, especially health data?





# INTRODUCTION

- Data is a vital raw material
- More scientific information has been generated in the last 5 years than in all of human history



# LEGAL FRAMEWORKS



## DATA GOVERNANCE ACT

**altruistic data  
sharing and  
reuse of  
public-sector  
data**



## EUROPEAN HEALTH DATA SPACE

**access to  
electronic health  
data for primary  
and secondary  
use**





DOES IT STILL MAKE SENSE  
TO TALK ABOUT DATA  
ALTRUISM AT ALL?



" the voluntary sharing of data on the basis of the **consent** of data subjects to process personal data pertaining to them, or **permissions** of data holders to allow the use of their non-personal data **without seeking or receiving a reward** that goes beyond compensation related to the costs that they incur where they make their data available for objectives of **general interest** as provided for in **national law** "



# WHAT IS DATA ALTRUISM

**Altruism**

**Voluntary sharing of personal or non-personal data without seeking rewards beyond cost compensation.**

**General interest**

**Healthcare and scientific research are examples of general interest goals**

**Opt-in**

**Requires informed consent for personal data; non-personal data can be shared by data holders**

**Organisations**

**Recognised data altruism organisations facilitate this process**



# HOW IT WORKS



1. **INDIVIDUAL / DATA HOLDER**  
(VOLUNTARY)



CONSENT / PERMISSION



2. **RECOGNISED DATA ALTRUISM ORGANISATION**  
(REGISTERED, NONPROFIT, RESPECTS DGA)



3. **DATA USERS**  
(e.g. researchers, healthcare entities)



COLLECTS, MANAGES AND SHARES  
DATA FOR GENERAL INTEREST  
PURPOSES  
(e.g. scientific research, public health)



USE THE DATA WITHOUT FINANCIAL GAIN  
FOR PUBLIC BENEFIT





## EXAMPLE: DATALOG

FIRST AND  
ONLY NON-  
PROFIT  
RECOGNISED  
ORGANISATION  
UNDER THE  
DGA.

BASED IN  
BARCELONA,  
PROMOTES  
WELL-BEING OF  
PEOPLE AND  
ENVIRONMENT.

COLLECTS AND  
ANALYSES DATA  
ON WATER,  
ELECTRICITY,  
AND GAS  
CONSUMPTION.



# HOW DOES THE EHDS WORK





# DGA VS EHDS

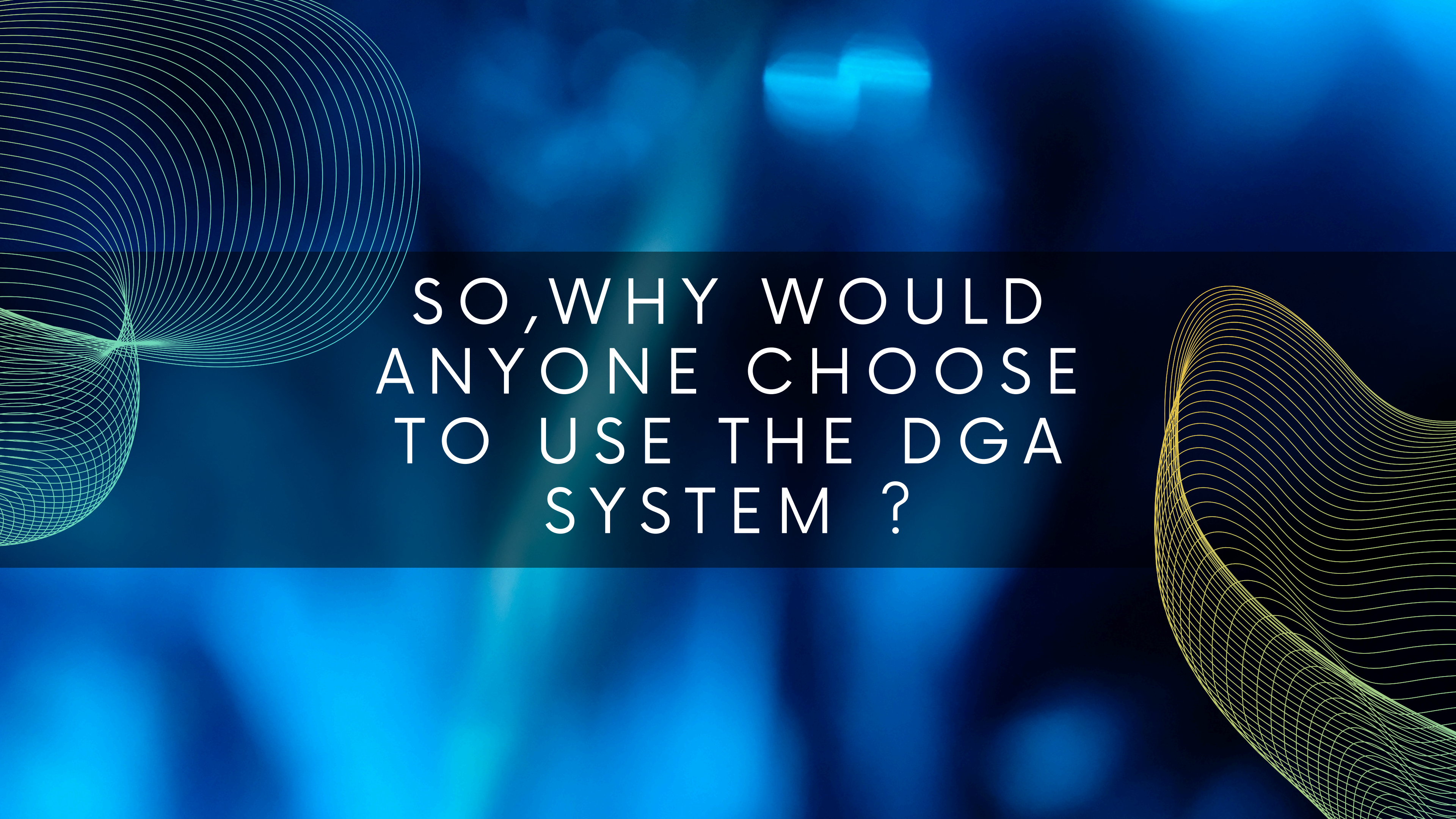
→ DGA requires **opt-in consent**, leading to possible **consent fatigue** and **bias**.

→ Recognised organisations must meet strict criteria, adding **bureaucratic burden**.

→ DGA scope limited to public sector; **private data excluded**.

→ EHDS uses opt-out, allowing **broad default access to health data for secondary use**.





SO, WHY WOULD  
ANYONE CHOOSE  
TO USE THE DGA  
SYSTEM ?



# DGA VS EHDS

→ DGA covers **broader data categories** beyond EHDS.

→ DGA offers **granular control and transparency**, empowering citizens.

→ EHDS opt-out model **limits user choice and information** compared to the DGA.



1. **the opt-out is general** — you cannot choose which research projects you want your data to be used for and which ones you don't.
2. you are **not informed about who** will use your data or **for what** specific purpose.
3. if you want to exercise your opt-out right, you must do so **before the data processing begins**; otherwise, it's no longer effective.



# CONCLUSIONS

- EHDS advances secondary use of health data with opt-out model.
- Data altruism remains relevant despite DGA limitations.
- Data altruism is complementary and essential for trust and citizen participation.





THANK YOU  
FOR YOUR  
ATTENTION

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The background features a dark blue gradient with lighter blue bokeh-like light spots. On the left, a yellow wireframe shape resembling a human head in profile is visible. On the right, a series of concentric yellow circles are arranged in a fan-like pattern.

QUESTIONS?