



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



EXAMPLE: DATALOG

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

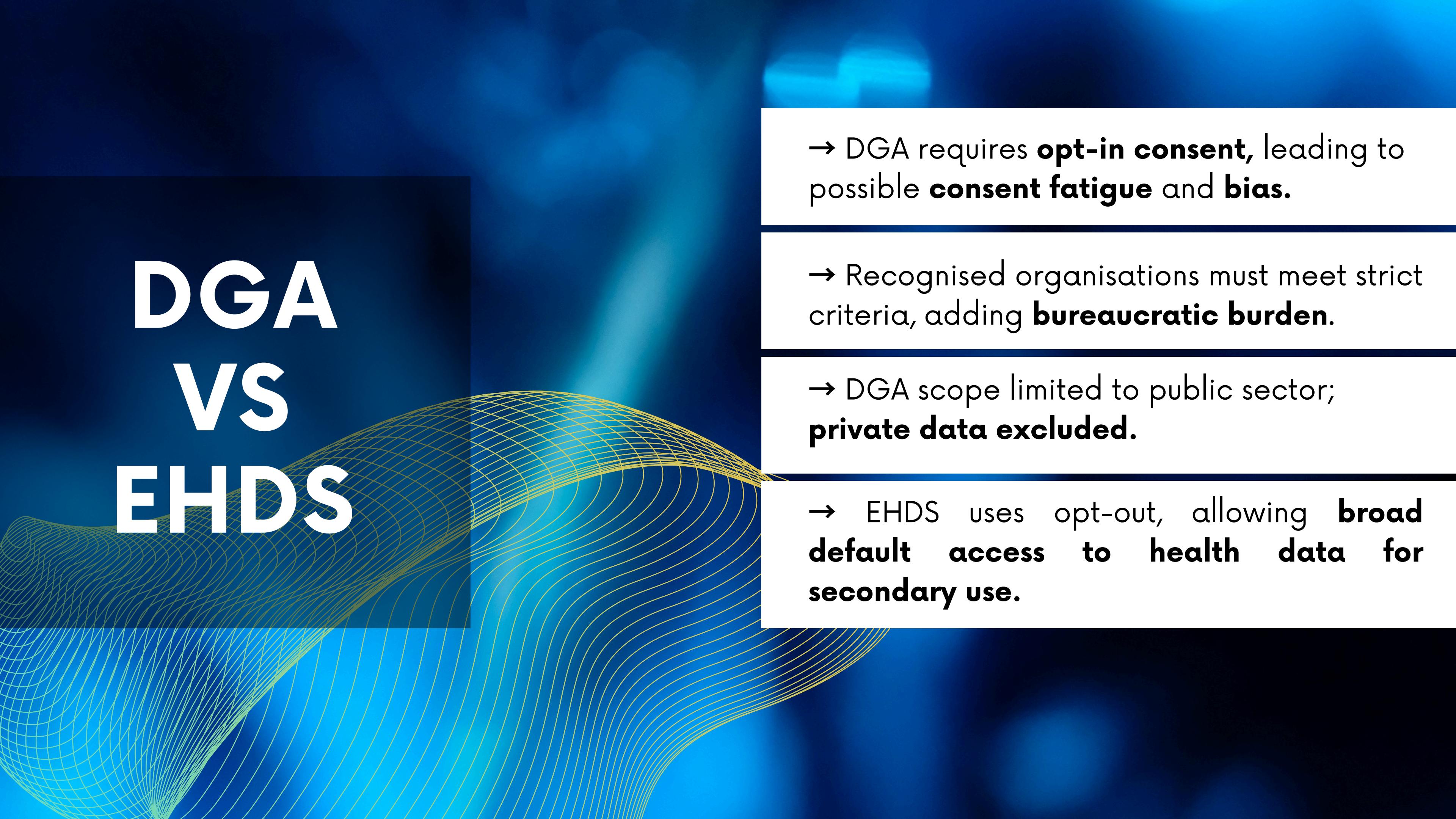
BASED IN
BARCELONA,
PROMOTES
WELL-BEING OF
PEOPLE AND
ENVIRONMENT.

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

HOW DOES THE EHDS WORK



DGA VS EHDS

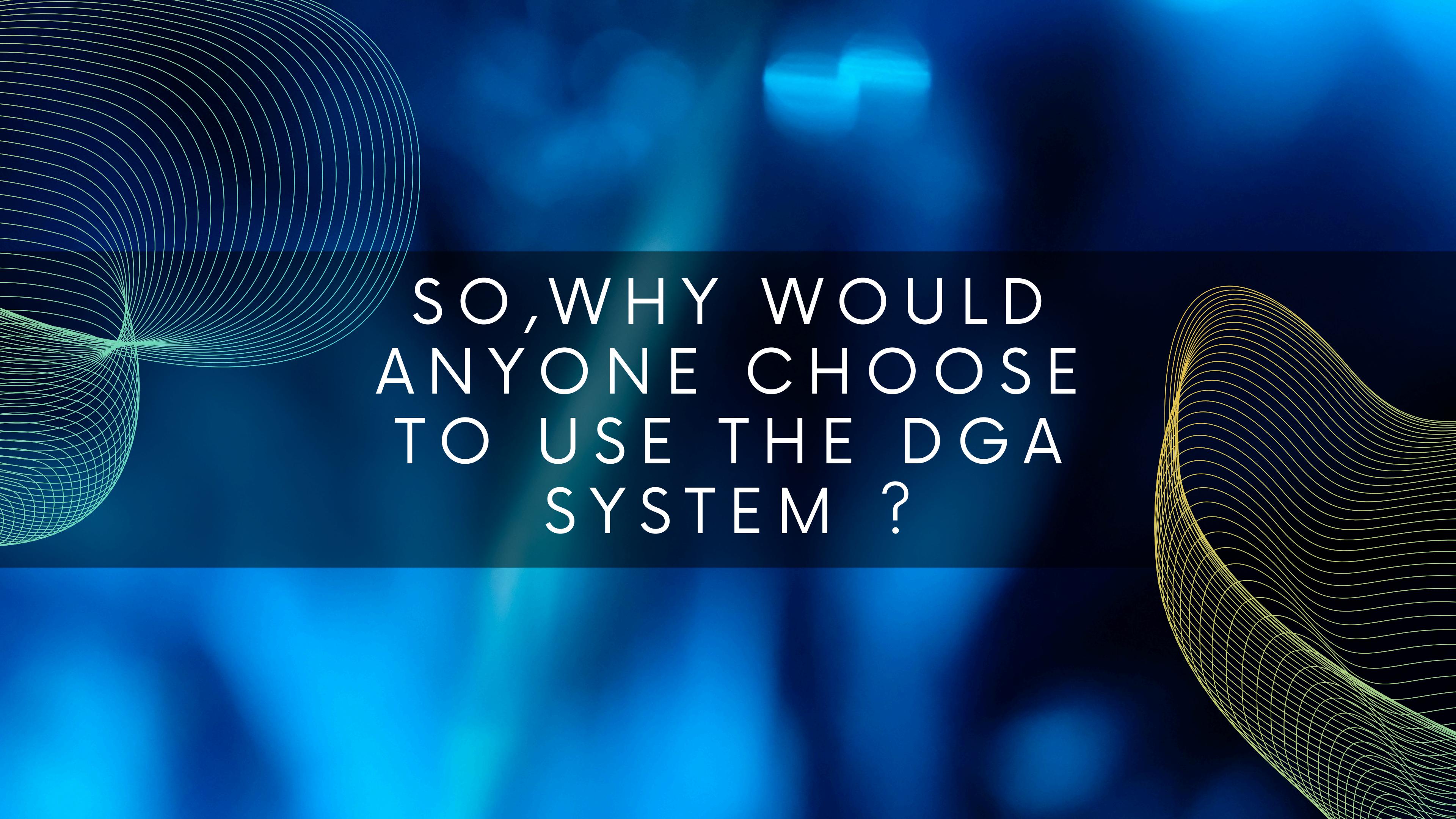
A large, abstract graphic on the left side of the slide features a dark blue square containing the text. Behind the square are several thin, wavy lines in yellow and light blue, creating a sense of depth and motion. The background of the slide is a dark blue gradient.

→ 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 YOU
ATTENTION

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The background features a dark blue gradient with a subtle radial blur effect. Overlaid on this are two sets of thin, white, wavy lines. One set of lines forms a large, organic shape on the left side, resembling a stylized head or a series of concentric shells. The other set of lines forms a similar organic shape on the right side, also resembling a stylized head or a series of concentric shells.

QUESTIONS?