Citizen-led data cooperative for COVID19: the CO3 project

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"Data is the raw material of the 21st century, and the question ‘Who owns that data?’ will decide in the end whether democracy, a participatory social model, and economic prosperity can be combined."

ANGELA MERKEL
A NEW CONTEXT

Social
Changes in the capacity of citizens and social demands

Technological
Data-driven innovations in technological developments & research

Economic
Economic pressure on public health systems & opportunity for setup a new health system.
A NEW CONTEXT

- My data is mine (GDPR)
- Donor Citizens
- Data is not easily accessible
- More with less
- Our data cures

COVID19
OUR VISION

Help citizens to manage their personal and health data and share with scientific research projects. Help researchers to access more value data.

HOW DO WE DO IT?

Through a citizen-led personal data data cooperative
OUR VISION

DATA KEEPERS
- Public health centres
- Private health centres
- Apps/wearables/devices
- Personal

DATA USERS
- Research centres
- Universities
- Research units in companies

Cooperative of citizens
EUROPEAN DATA GOVERNANCE
A NEW APPROACH FOR THE DIGITAL DECADE
#DigitalEU
OUR WORK

2016
Research

2017
Salus.Coop Foundation

2018
TRIEM

2020/21
Salus.APP

2020/21
CO3 Project
TRIEM
Conditions for data donation

- Who requests data
- Which data is requested
- What is research conducted for
- How will results be shared

600 participants answering more than 8,000 scenarios
Only health/social: data will only be used for health and / or social studies.

Non-commercial: research projects will be promoted by entities who support general interest such as public institutions, universities and foundations.

Shared results: results of the research will be accessible at no cost.

Maximum privacy: all data will be pseudo anonymised prior to use.

Complete control: you will be able to cancel or change the conditions under which your data can be accessed at any time.
We are developing a mobile application that allows the exercise of sovereignty over the personal data and conditional donation with total privacy, security, traceability and transparency.

**SALUS.COOP APP**

- The data comes from health data hosted on Google Fit / HealthKit
- The data will be stored in a decentralized storage system (IPFS)
- The data is pseudo-anonymized and protected using cryptographic techniques.

*End-to-end data encryption*
OBJECTIVE
To create a cohort of citizens who provide their data for research on COVID-19. Promote, among the member communities of cooperatives, the donation of their personal data for non-profit health research.

Co-promoter:

More info:
https://www.saluscoop.org/proyectos/co3
What we have

- 3 Public Research Centers / 3 COVID19 Projects using citizen data
- Support of the Catalan Cooperative Movement
- Support of the Catalan Government Digital Policy and MWC Foundation
- Tool for recruiting citizens as potential donors of personal data for research (license)
- Tool for citizens to transfer (pseudo anonymized) mobile data (geoloc. + podometer-steps) and answer surveys for the Research Centers
Will you join us?

www.salus.coop
THANK YOU!

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