Mobilising citizen science in support of health research and health services provision

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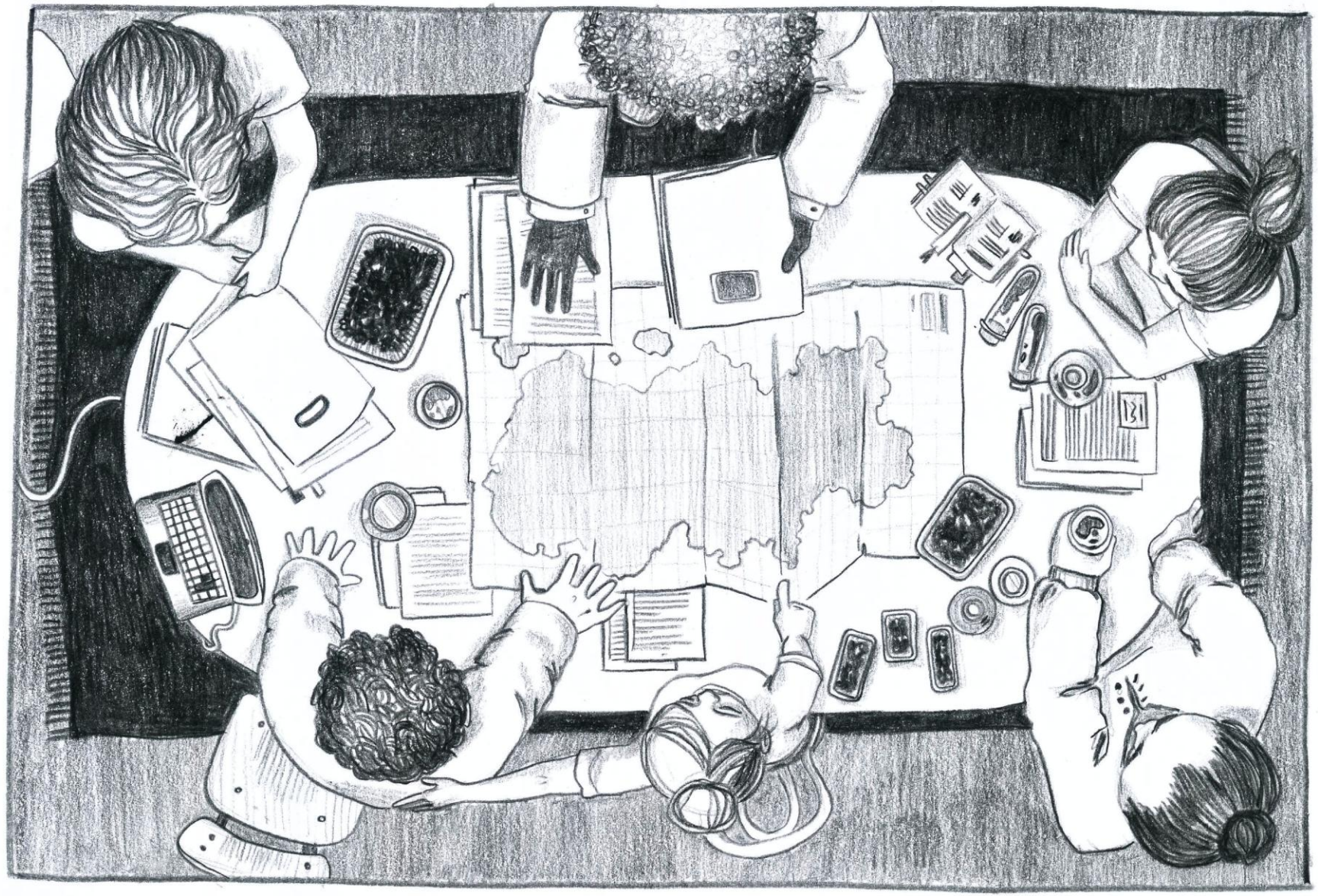
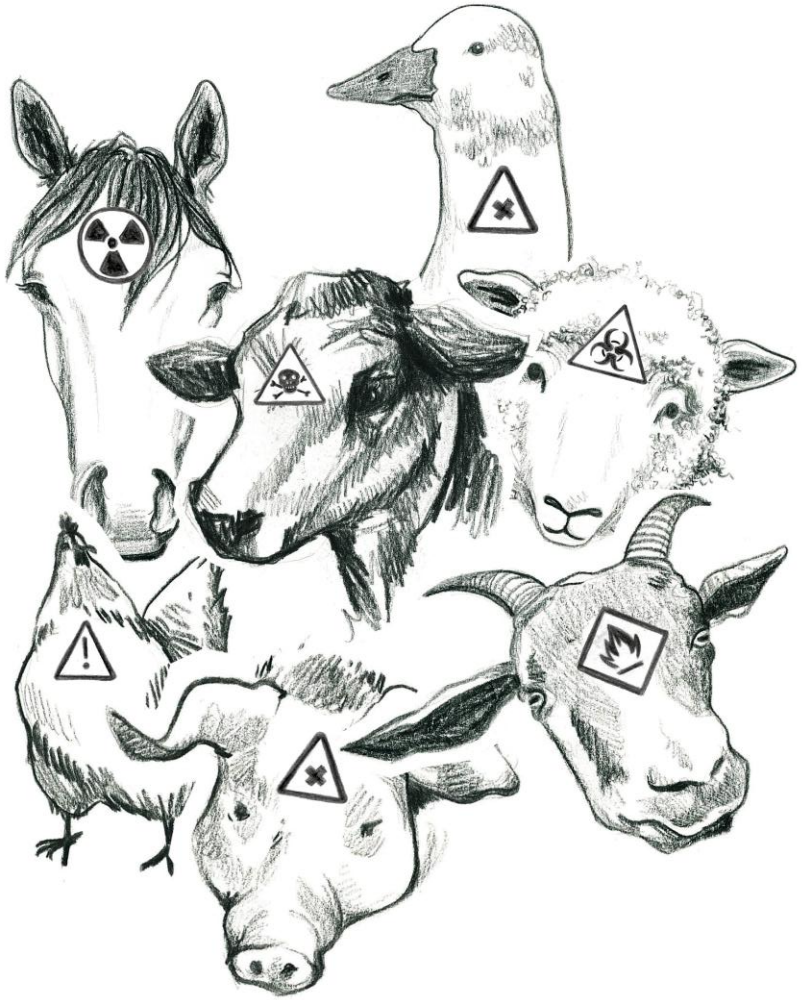
PADOVA SCIENCE, TECHNOLOGY AND INNOVATION STUDIES

UNIVERSITÀ DEGLI STUDI DI PADOVA

1 A few words on my passion

How did I discover the charming field of citizen science






REGIONE BASILICATA
PROVINCIA DI MATERA
PROVINCIA DI POTENZA
LucAS
LUCANIA · AMBIENTE E SALUTE


LucAS Agorà
19 MAGGIO 2025
Ore 16:30
MELFI
"Sala Consiliare"
SALUTI ISTITUZIONALI
Giuseppe MAGLIONE - Sindaco di Melfi
Laura MONGIELLO - Assessore Ambiente e Transizione energetica Regione Basilicata
INTRODUZIONE
Michele BUSCIOLANO - Responsabile Esecutivo Progetto LucAS
INTERVENTI
Rosa Anna CIFARELLI - Responsabile Scientifica Progetto LucAS
Enzo ALLIEGRO - Ordinario di antropologia, Università di Napoli Federico II, Fondazione Ambiente Ricerca Basilicata - FARBAS
EPIDEMIOLOGIA GEOGRAFICA E SORVEGLIANZA EPIDEMIOLOGICA NEL PROGETTO LucAS. PRIMA FASE: I QUESITI DI RICERCA
Annibale BIGGERI - Professore di statistica medica, Università di Padova, Componente CTS Progetto LucAS
IL RUOLO DI ASP NEL PROGETTO LucAS
Pier Luigi GIGLIUCCI - Direttore Generale f.f. ASP Potenza
DIBATTITO
CONCLUSIONI
Cosimo LATRONICO - Assessore Salute, Politiche per la Persona e PNRR Regione Basilicata
MODERA: Tommi GUERRIERI - Giornalista
20 MAGGIO 2025
Ore 16:30
ROTONDELLA
"Palazzo Ricciardulli"
SALUTI ISTITUZIONALI
Gianluca PALAZZO - Sindaco di Rotondella
Laura MONGIELLO - Assessore Ambiente e Transizione energetica Regione Basilicata
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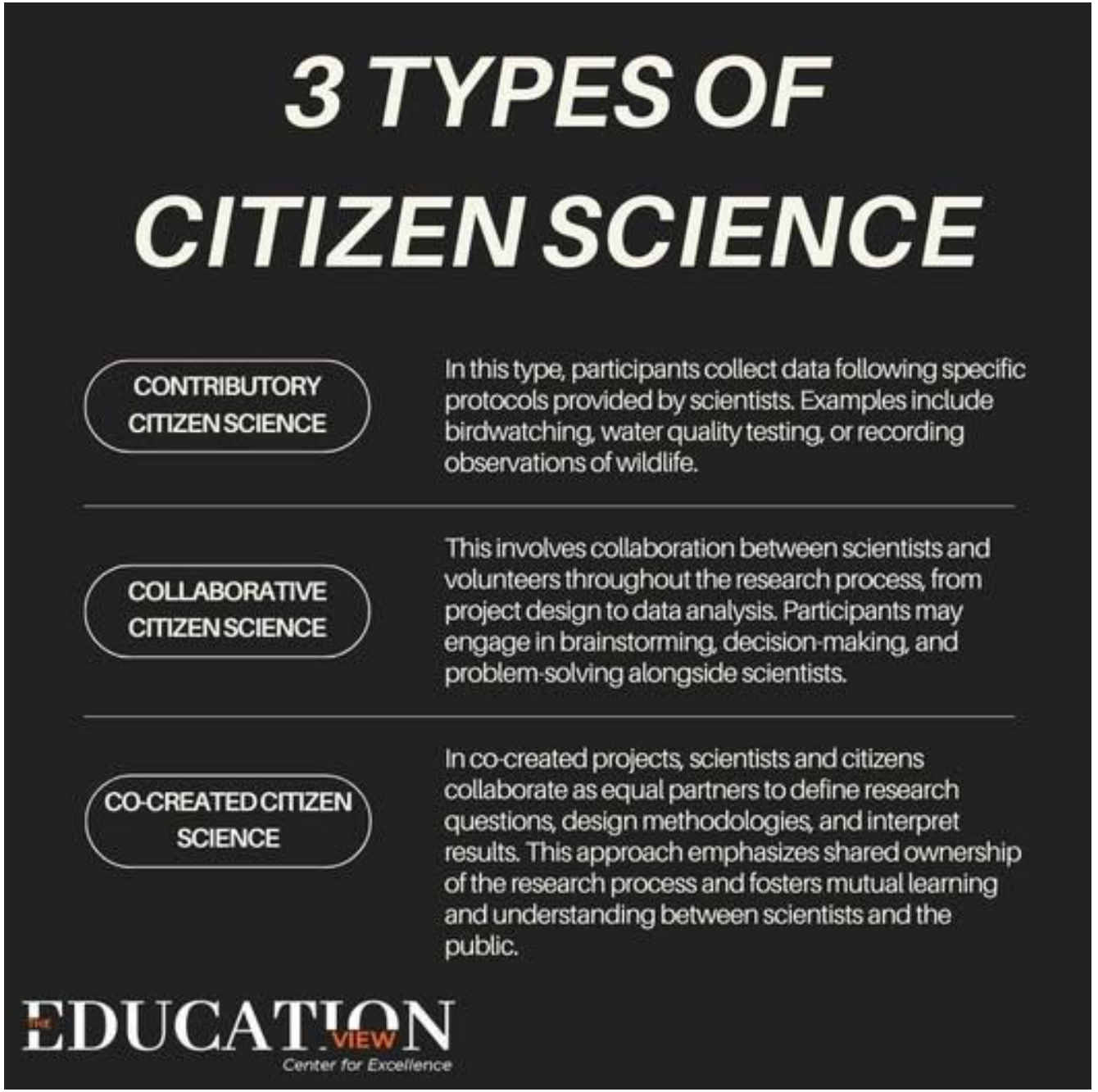
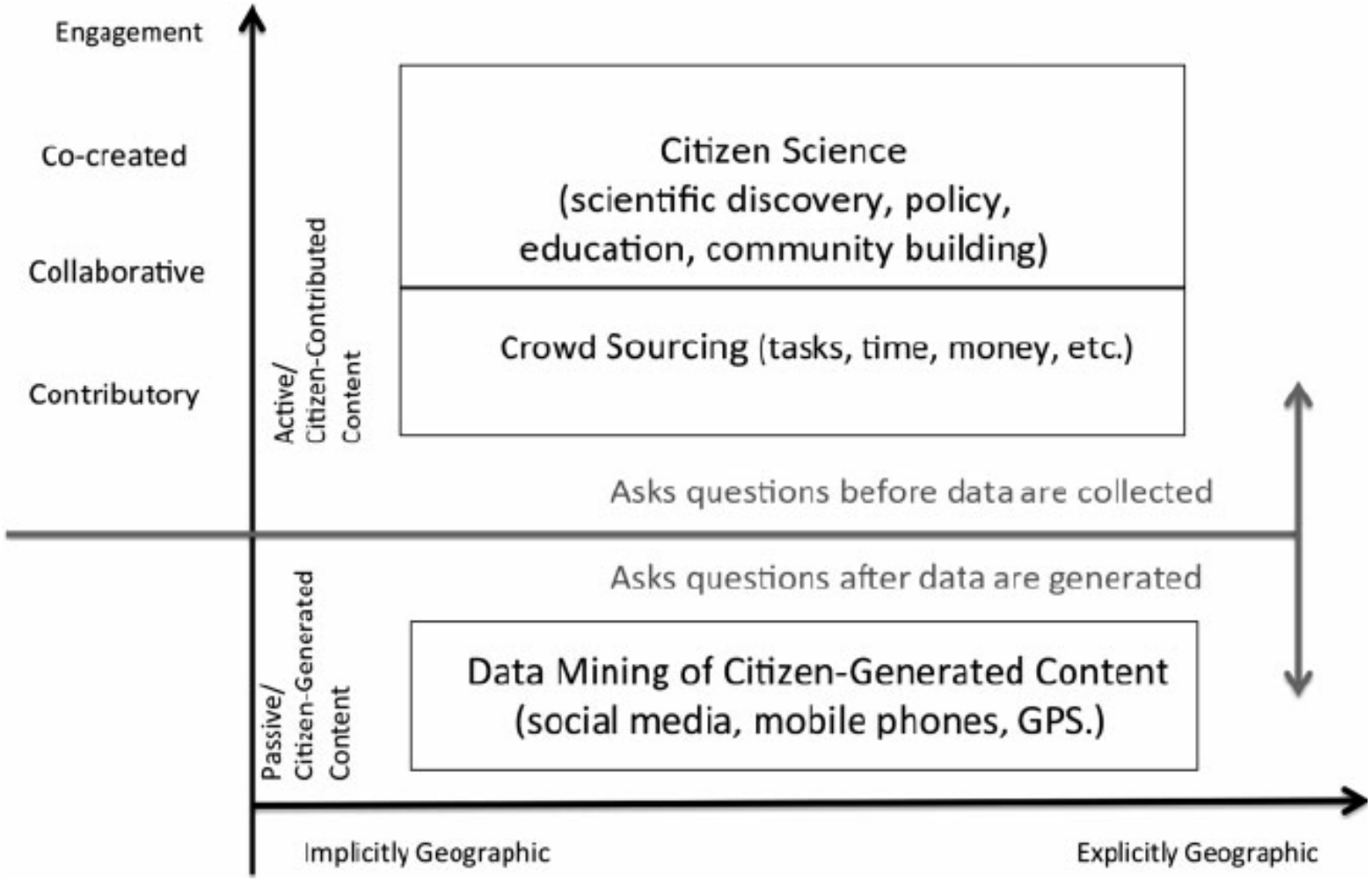
segreteria organizzativa
FARBAS

2 So what is citizen science?

In search of a definition, blurring concepts


3 TYPES OF CITIZEN SCIENCE
CONTRIBUTORY CITIZEN SCIENCE
In this type, participants collect data following specific protocols provided by scientists. Examples include birdwatching, water quality testing, or recording observations of wildlife.
COLLABORATIVE CITIZEN SCIENCE
This involves collaboration between scientists and volunteers throughout the research process, from project design to data analysis. Participants may engage in brainstorming, decision-making, and problem-solving alongside scientists.
CO-CREATED CITIZEN SCIENCE
In co-created projects, scientists and citizens collaborate as equal partners to define research questions, design methodologies, and interpret results. This approach emphasizes shared ownership of the research process and fosters mutual learning and understanding between scientists and the public.
THE EDUCATION VIEW
Center for Excellence



Craglia, Max & Shanley, Lea. (2015). Data democracy: Increased supply of geospatial information and expanded participatory processes in the production of data. International Journal of Digital Earth. 8. 1-15. 10.1080/17538947.2015.1008214.

ExCiteS | Extreme Citizen Science

UCL

Comparing

Goals and environment	5C's	Levels of participation
	Consulting	
Conservation/Investigation/ Virtual/Education	Contributory	Crowdsourcing/ Distributed Intelligence
(Conservation/ Investigation)	Collaborative	
(Conservation)	Co-created	Participatory
Action	Collegial	Extreme Citizen Science

Environmental citizen science	Civic environmental monitoring	Civilian science and civilian monitoring
The practice in which non-professional participants contribute to data collection and in some cases data analysis to advance research in the environmental field.[1] It always entails a scientific component (e.g., systematic observations) and may be supported by professional scientists. Context: peacetime. *Note*: the reference to 'citizenship' is detached from its legal definition being rather a synonymous of 'people'.	The use by ordinary people of monitoring devices such as sensors or their senses such as smell to detect environmental issues.[2] It may or not entail a scientific component (e.g., anecdotal observations). Context: peacetime.	The application of citizen science and civic monitoring methodologies to record and report environmental impacts caused by AC.[3] It includes both systematic data collection and analysis, and non-systematic observations (e.g., based on personal stories or individual experiences). Context: both during and after an AC.

[1] Muki Haklay et al., 'What Is Citizen Science? The Challenges of Definition' in Katrin Vohland et al. (eds), *The Science of Citizen Science* (Springer 2021).
[2] Anna Berti Suman, *Civic Monitoring for Environmental Law Enforcement* (Edward Elgar 2024).
[3] Doug Weir, Dan McQuillan & Robert Francis, 'Civilian science: the potential of participatory environmental monitoring in areas affected by AC' (2019) 191 Environmental Monitoring and Assessment 618.

3 Citizen science in health research

How the practice is contributing to patients' engagement, knowledge production and community-based research

Citizen science for health

Health is relatively under-represented in citizen science, despite the fact that it is a very diverse and promising domain. Projects and approaches may range from applications in the domain of public health, to personal science approaches associated with the Quantified Self movement, and every shade in between. At the same time, the engagement of patients in health research has a long tradition, even though their impact on e.g. decision making on research questions, methodology, ethics, analysis and data management remain limited so far. Citizen Science has a huge potential contribute to innovative health research, as well as to society.

This Working Group believes that to unlock this potential there is a need to collaborate more intensely across borders and domains. The purpose of the Working Group is hence *to increase the social and scientific impact of citizen science for health*. Its main objectives are:

1. To create a community of stakeholders dedicated to promoting and developing Citizen Science for health by fostering dialogue and collaboration them
2. To develop and disseminate tools, methods, ethical frameworks and training material for CS4H
3. To enhance the visibility and potential of CS projects in the health domain

The University of Nottingham

Citizen Science for Mental Health

We want to identify the ways individuals manage their mental health challenges, by generating a list of self-management strategies that can enable better support in the future.

WE NEED YOUR HELP TO ANSWER

"How do people manage their mental health challenges?"

WHAT YOU WILL DO

Choose from a list, methods you use to manage your mental health.

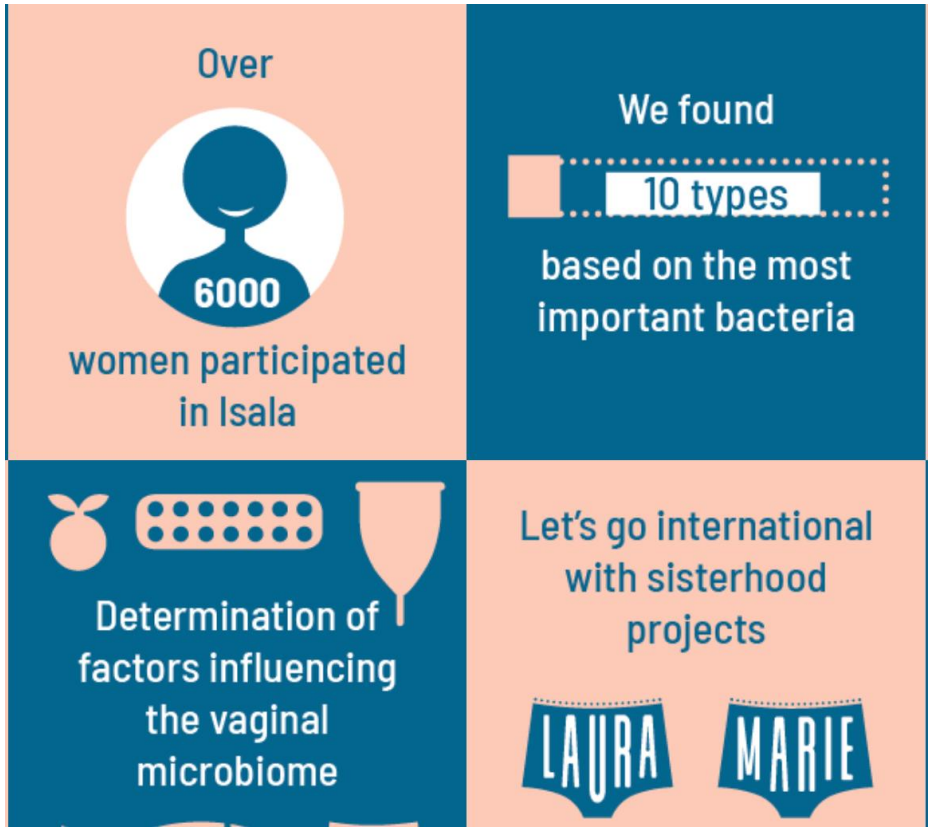
TO PARTICIPATE YOU MUST BE

- 18 years or older
- Resident in the United Kingdom

SCAN FOR MORE DETAILS

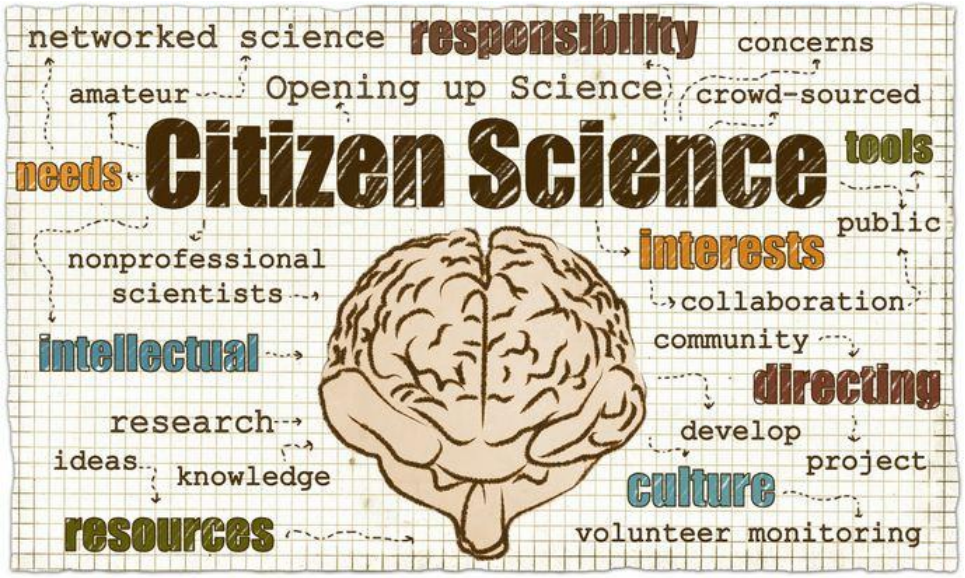
SUBSCRIBE TO OUR MAILING LIST

The project has been funded by UK Research and Innovation (UKRI).



Ethical principles

Ethics belong to everyone involved in citizen science



European Data Protection Law Review > Volume 4 (2018), Issue 3 > Pages 284 - 295

Challenges for Citizen Science and the EU Open Science Agenda under the GDPR

open-access

Anna Berti Suman, Robin Pierce

DOI https://doi.org/10.21552/edpl/2018/3/7

Keywords: Citizen Science, Open Science, GDPR, secondary use of health data, research exemption

Full Text (PDF) Full Text (HTML)

4 Citizen science for health service provision

Exploring data altruism, personalization from below and related challenges

The 'Cochrane Crowd', a Citizen Science initiative aimed at categorizing and summarising healthcare evidence in order to 'make better healthcare decisions'.

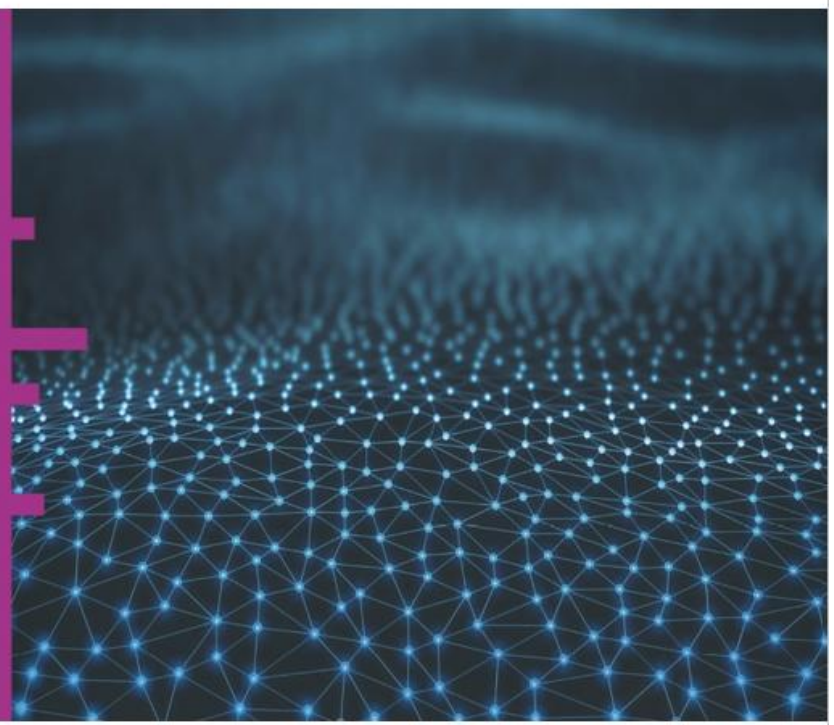
Cochrane Crowd

You can make a difference

Help us curate and deliver health evidence

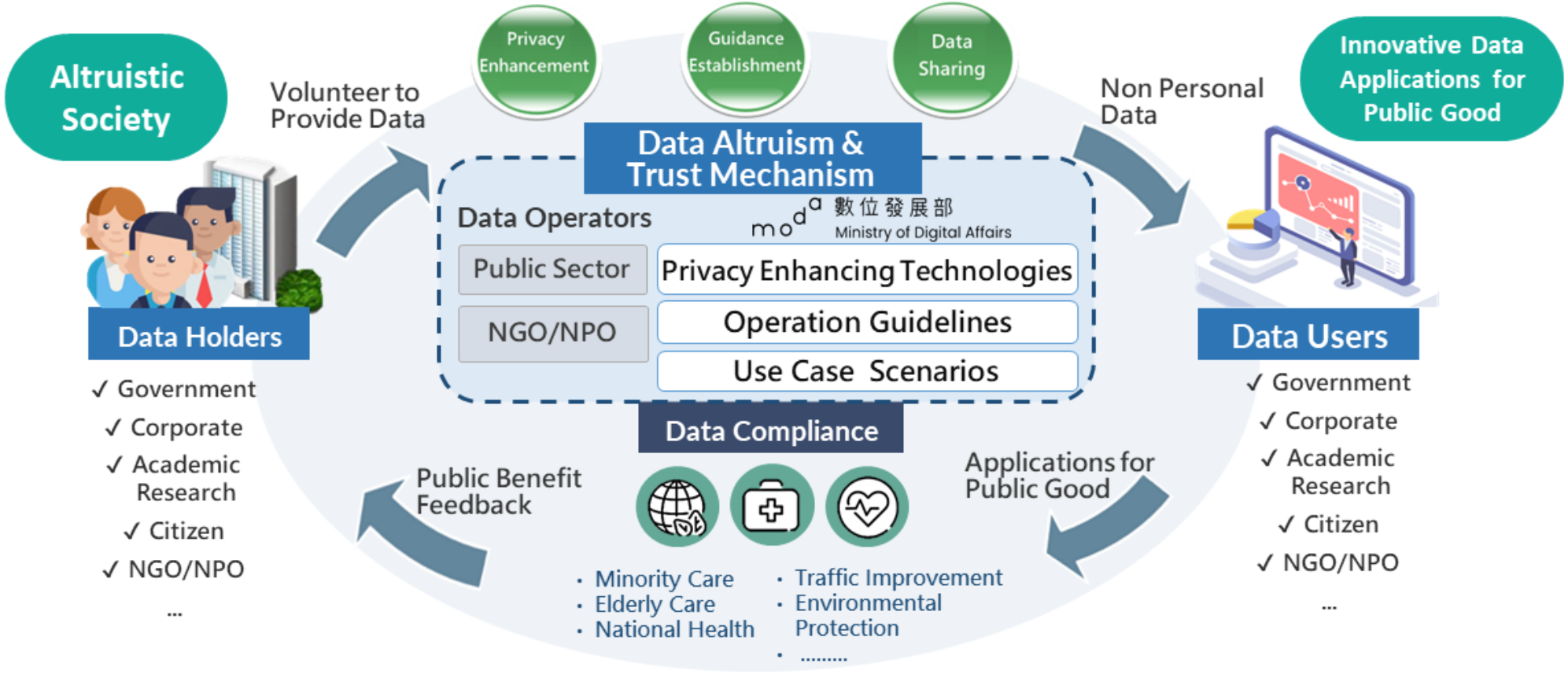
crowd.cochrane.org

@cochrane_crowd | crowd@cochrane.org



Free, aware, actual consent?

Data Altruism Ecosystem



SALUS.COOP som una **cooperativa de donants de dades per a la recerca per al Bé Comú.**

La recerca ens permet generar informació que un cop analitzada esdevé l'evidència necessària per a la presa de decisions. Des de Salus.Coop **impulsem la recerca com a vehicle de transformació social.**

Les dades són el nou patrimoni personal i social. L'ús que en fem és **determinant a l'hora de dibuixar el mapa de la realitat que ens envolta.** Per això des de Salus.Coop treballem cada dia per a **garantir l'anonimat i l'impacte social positiu dels projectes als quals nodreixen.**

A través de l'App Salus.Coop connectem donants i recercaires de forma segura: **el control és del donant, les dades són anònimes i el recercaire només accedeix al que s'indica a l'acord, que és senzill i transparent.**

Thank you for your attention. Questions?

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