A Colourful Toolbox

Health Citizen Science under the GDPR

Visual Report: Reflections from a Brocher Foundation Journey

By Anna Berti Suman, Alice Toietta and all workshop participants

FONDATION BROCHER

Introduction

On 12 and 13 October 2021 we convened a workshop on Health-Citizen Science Dilemmas under the EU General Data Protection Regulation 2016/679 (GDPR): the page of the event is available at https://www.brocher.ch/fr/events/417/health-citizen-science-dilemmas-under-the-gdpr. The workshop explored the scarcely researched implications of the GDPR for the active sharing of (environmental) health data within the framework of Citizen Science projects. Citizen Science is the active public involvement in scientific research (https://www.nature.com/articles/d41586-018-07106-5). We discussed how data processing requirements under the GDPR may affect the advancement of Citizen Science for (environmental) health research, from a theoretical and empirical perspective.

We organized the workshop at the Brocher Foundation, Geneva, whose mission is to encourage research on the ethical, legal and social implications of new medical technologies. Its main activities are to host visiting researchers and to organize workshops and summer academies.

The first day of the workshop was mostly dedicated to take stock of the current reflections from academic scholarship on the topic. During the second day, we investigated concrete cases where the GDPR and (environmental) health Citizen Science intersect, based on the experience of the participants. We concluded identifying possible ways forward to ensure that the potential of Citizen Science for research will not be unduly curtailed by the advent of the GDPR but also to ensure that Citizen Science is implemented in ways that are consistent with the GDPR. Lastly, we pinpointed gaps and future research questions that we deem should be explored.

The workshop was accompanied by two artists, one who captured the discussions and interactions among the physical and virtual audiences with a live drawing approach, the other who worked and is working on realizing visual consent forms, also inspired by the workshop reflections. This booklet is the result of our collective brainstorming and note-taking, and of the live drawing during the event.

At the end of this booklet, you can find the list of bios of the participants* and the visual consent forms**. Literature used in the workshop, slides and other resources provided by the participants can be found at: https://drive.google.com/drive/folders/19pfQkEQX_AE4QmWpfQdMOTh-U54Rpief?usp=sharing.

Program

Morning session:

— Setting the scene: the active sharing of health data within the framework of Citizen Science projects and in the broader context of Open Science [Anna Berti Suman]
- The symposium idea and background
- The EDPL study of 2018, 3 years after

— Roundtable on 'sensing' the expectations for the symposium among the participants

— Health Citizen Science and the General Data Protection Regulation
- Citizen science in the medical setting [Robin Pierce]
- Health policy encounters Citizen Science [Torben Sigsgaard and Carsten Lyng Obel]
- Public health interactions with citizen science [Sabine Wildevuur]

— Ethical dimensions of (health) research with citizen scientists
- A needed focus on diversity in assessing Citizen Science [Dana Mahr]
- New technologies, ethics and data protection: between law in the books and law in action [Carlo Botrugno]

— Reactions from the participants

— Live drawings explained by artist [Alice Toietta]

Afternoon session

— Tensions and dilemmas between data protection and open science
- From the 2018 study to present experiences from the SensJus project [Anna Berti Suman]
- The pilot idea of open access, visual consent forms [Bela Pinheiro]

— The role of law and regulations in harmonizing openness and data protection
- Resisting a neoliberalism trend, the perspective of consumer law [Motahareh Bollon]
- The JRC study, data management in Citizen Science [reflections from Scassa and Tsinaraki]
- The Holland Health Data Cooperative take on the GDPR [Gaston Remmers]

— Health Citizen Science from the lens of sociology
- When health Citizen cience meets environmental crises [Bruna De Marchi]
- From self-tracking to self-expertise [Nils Heyen]
- COVID-19 vaccination governance: valuing knowledge production and expertise in contemporary democracies [Katharina Paul]

— Reactions from the participants

— Live drawings explained by artist [Alice Toietta]

## October 13 – DAY TWO

Morning session
– Focusing on (environmental) health Citizen Science
cases, benefits, implications & challenges:
- The experience of Pulsaqua in supporting Open
Science [Sandra de Vries]
- Data management in the NOSE project, ARPA Sicilia
[Anna Abita]
- Experiences from the CitiesHealth project [Annibale
Biggeri e Bruna De Marchi]

– Follows on ongoing projects and pilots:
- Ethical dimensions of participatory epidemiology
[Antonella Ficorilli]
- The TOPFIT Citizen Lab in Twente [Karin Van Leersum]
- The CSI COP project on GDPR and apps [Huma Shah]
- The Patient Science project [Nils Heyen]

Afternoon session
– Tensions between GDPR concerns and access to information held by authorities in matters concerning public and environmental health [Veronica Dini; Anna Berti Suman]

– A network for Health Citizen Science: the ECSA Working Group experience, the survey [Gaston Remmers; Sabine Wildevuur]

– Reflections towards a future research agenda and advice for practitioners

– Final compilation of live drawings explained by artist [Alice Toietta]

Day 1
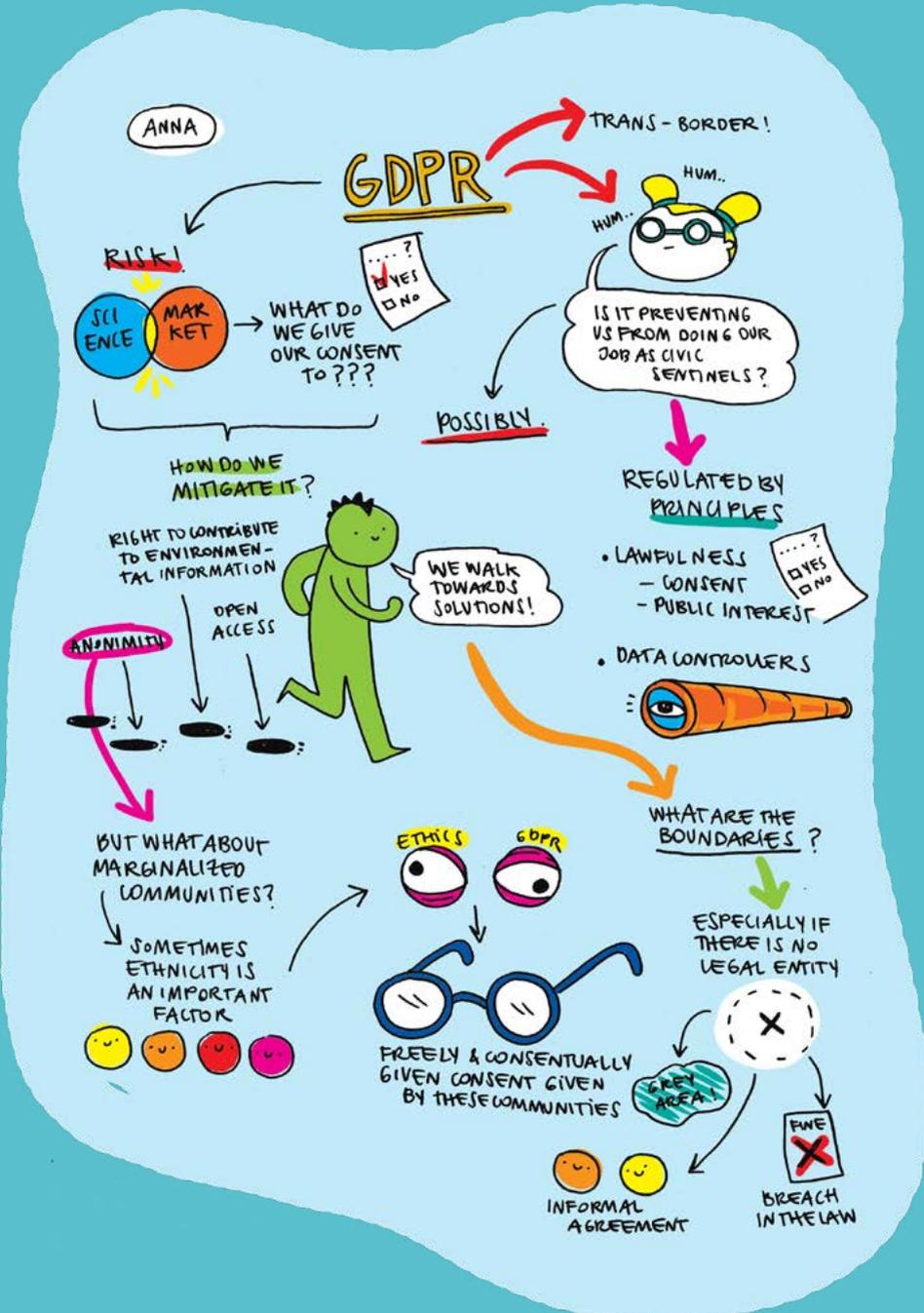
Anna Berti Suman

● The study from 2018, in the aftermath of the advent of the GDPR, that inspired this workshop can be found in open access at: https://edpl.lexxion.eu/article/edpl/2018/3/7
● But then a pandemic arrived, and also our attitude towards sharing (health) data for the public interest changed.

Audience:
● What about spontaneous forms of Citizen Science that are very unstructured and grassroots-driven?
● We may end up with the survival of only citizen science initiatives able to set up GDPR compliance mechanisms, likely only the larger scale, EU-funded projects.

Resources:
● the Wikipedia page on Citizen Science: https://en.wikipedia.org/wiki/Citizen_science
● A GDPR overview page: https://gdpr.eu/

Robin Pierce
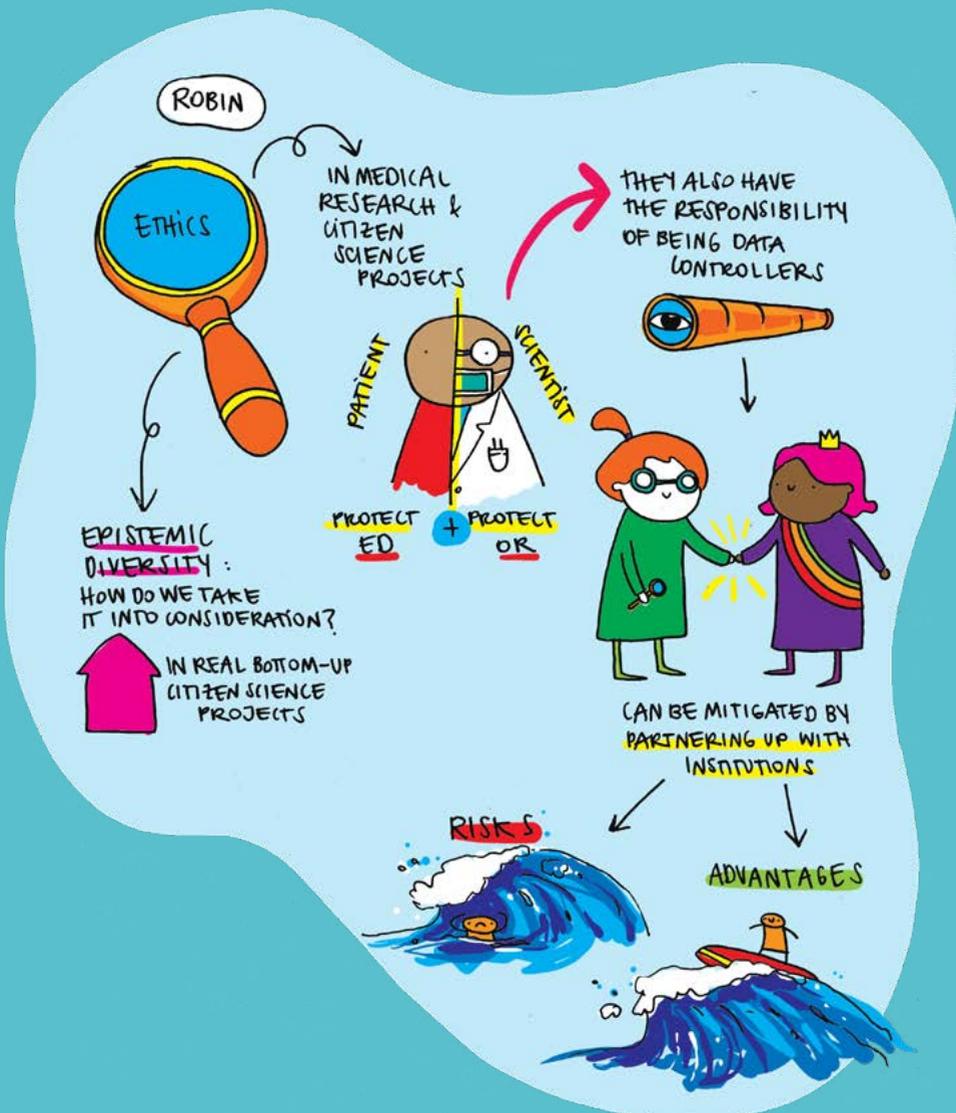
● Every citizen is potentially a principal investigator [Prainsack], therefore they can potentially be a data controller: can they face this burden?
● Personal data is needed to ensure representativity of the citizen science initiative, but how can we ensure that benefits stemming from an initiative are equally shared?

Audience:
● Making the (in)visibility of health disparities emerge in the science context.
● Through acknowledging epistemic diversity in Citizen Science, we create spaces for counter-cultures.

Resources:
● Our Voice: Citizen Science for Health Equity page:
https://med.stanford.edu/ourvoice.html
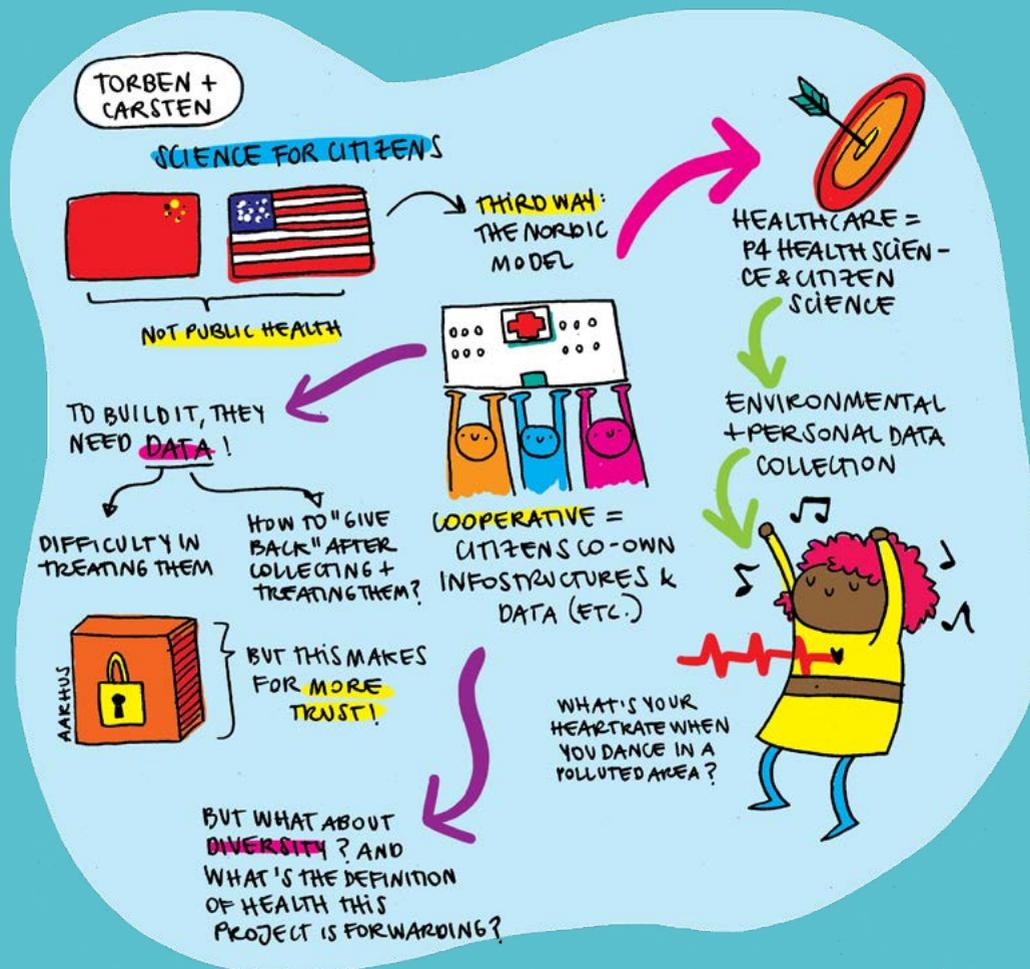
Torben Sigsgaard & Carsten Lyng Obel

● The cooperative model as an example of a WAY FORWARD to balance data sharing and data protection.
● A new social contract based on the trust of citizens towards an health data cooperative, in which real world data like environmental data are linked to clinical data.

Audience:
● Which implications for GDPR compliance does this cooperative model have?
● May this risk to end up being a paternalistic approach and hide a governamentality drive? It depends also on which concept of health you adopt...

Resources:
● The initiatives discussed: https://healthd360.dk/en/; http://nordichealth2030.org/
● The Rochdale principles on the cooperative model: https://en.wikipedia.org/wiki/Rochdale_Principles; an experience from the Danish world https://priway.eu/
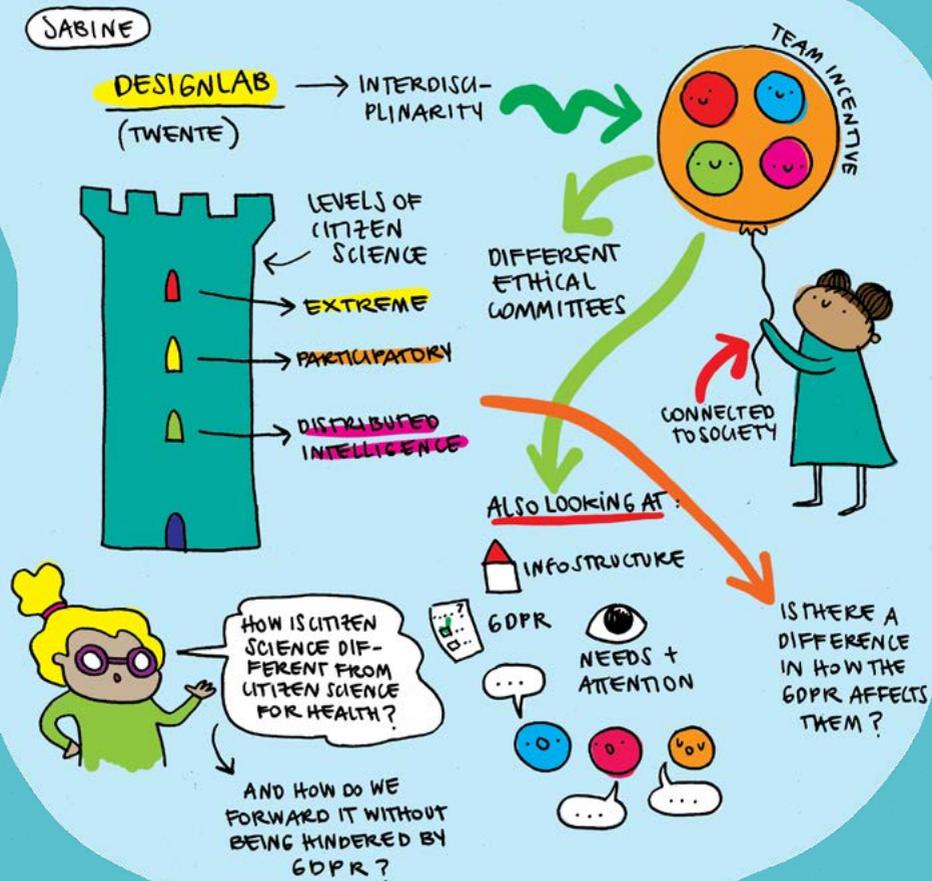
Sabine Wildevuur

● Going from extreme Citizen Science to crowdsourcing [Haklay], how does GDPR apply in these different manifestations of participatory research?
● Is health Citizen Science a distinctive form of citizen science that requires a particular approach? In any case, the FAIR (findability, accessibility, interoperability, and reusability) data principles should be embedded in it.

Audience

● A WAY FORWARD could be training Ethical Review Boards of these specificities of Health Citizen Science.
● The experience of Citizen Science hubs as places for sharing knowledge and best practices?
● Taking inspiration from past categorization of participation such as the ladder of citizen participation [Arnstein] to understand current manifestations of Citizen Science.

Dana Mahr
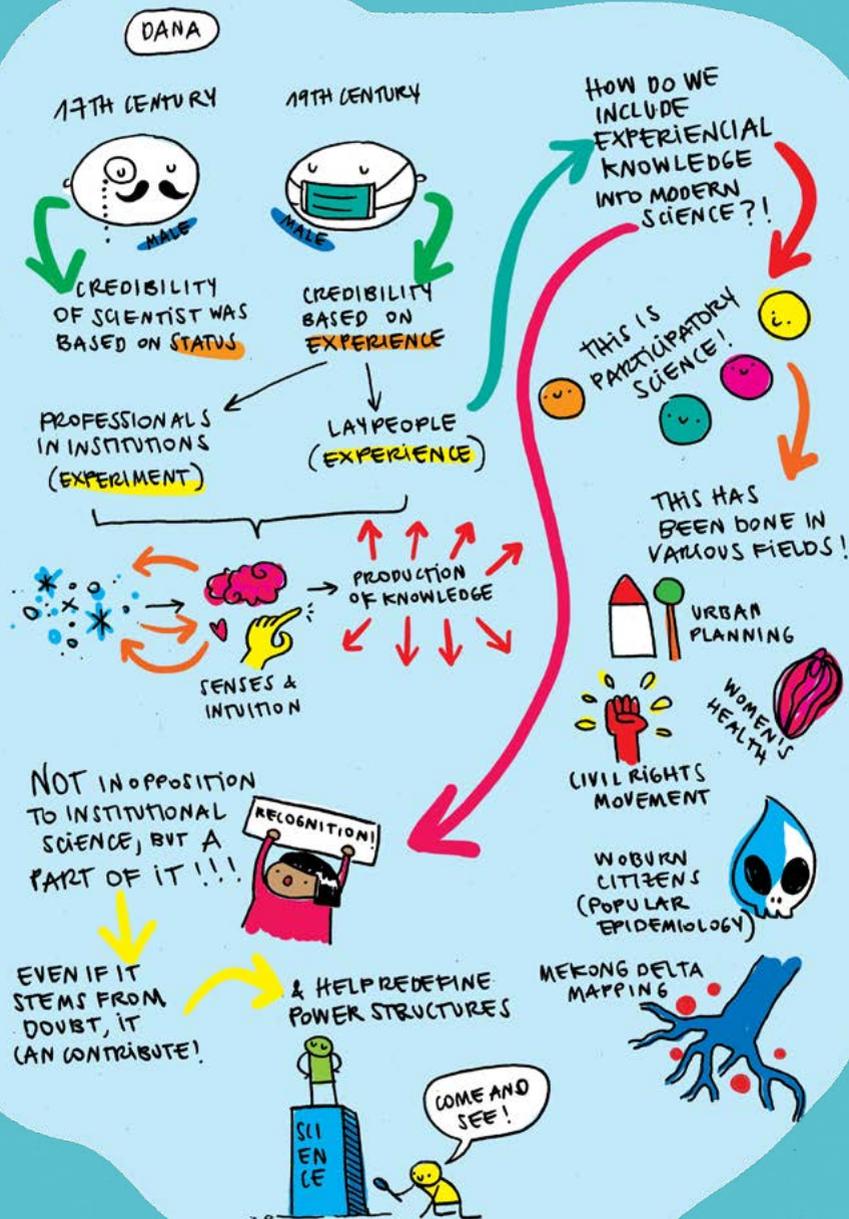
● We need to investigate the story of how citizen scientists built their credibility: in biodiversity Citizen Science there is a more established tradition of civic engagement, this is not the case for Health Citizen Science; but its roots can be found in the radical science movement.

● Towards a legitimization of Citizen Science as an intimate body experience and as science by intuitions? Fighting for local knowledge inclusion in planning [Jacobs] and in mainstream medicine.

Audience:

● In the current crisis of trust towards institutions, Citizen Science can help the citizens feel closer to their governors and reconcile the breach of the social contract. Maybe trust stems from or working together?

Resource:

● The Knowledge of Experience (Mahr, Palgrave 2021): https://www.palgrave.com/gp/book/9789811637018
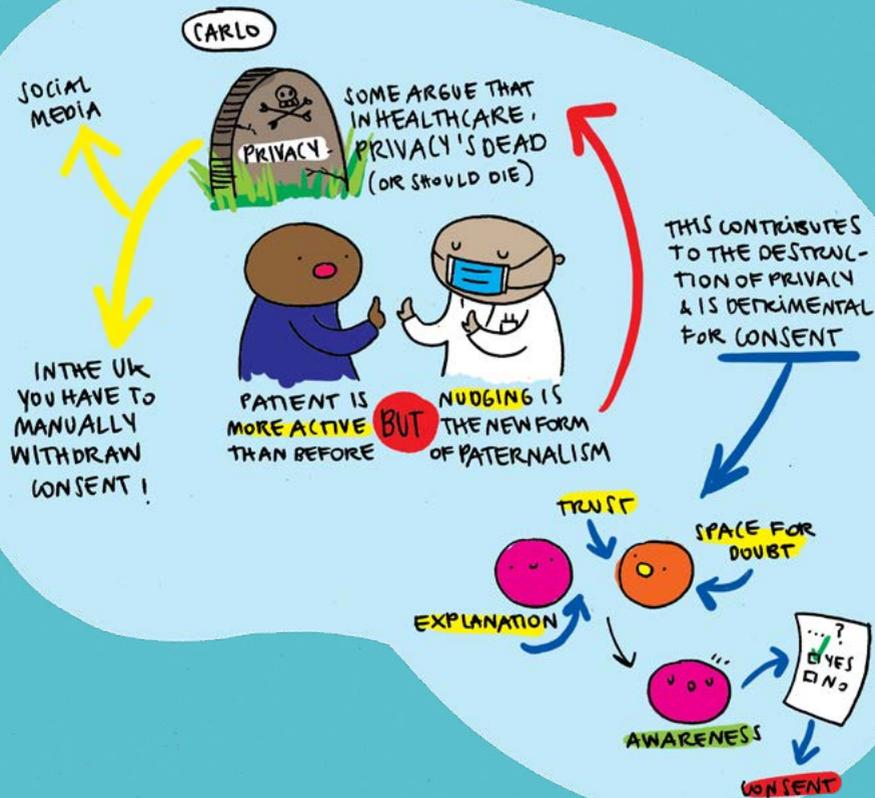
Carlo Botrugno

- Provocation: privacy must die [Caplan]?
- Bioethics as a way to defeat paternalism in healthcare
- A WAY FORWARD: maybe we should move from informed consent, which is just the last stage of a process, to informed awareness, i.e. a conscious engagement of the participant in all stages of the research process?

Resource:
- Caplan's blog post discussed: https://theheal-thcareblog.com/blog/2016/12/19/goodbye-pri-vacy-we-hardly-knew-ye/

ANNA

HUMANS ARE PRONE TO SENSING

CAN THE INFORMATION WE GATHER BE RE-COGNIZED BY SCIENCE & LAW ?

SENSJUS AIMS TO ANSWER THIS QUESTION

IN ENVIRONMENTAL LITIGATIONS

BASILICATA

HEAVY METAL CONTAMINATION

GDPR ISSUES

FORMOSA

NO PERSONAL DATA ON HEALTH

CAN THE LEVEL OF PARTICIPATION BE MEASURED ON HOW MUCH EXPERTISE THEY BRING TO THE RESEARCH ?

SHOCK-DRIVEN

STATUS

& WHAT IT IS MEASURED BY.

ALSO WHICH PERSPECTIVE WE ASSUME!

HOW DO WE PUT ALTIVISM & TRUST INTO THIS DISCOURSE ?

YUP!

MMM..

ESPECIALLY WITH REGARDS TO GOVERNMENTS/ POLICY MAKERS

AKNOWLEDGING IT HELPS!

Anna Berti Suman & Bela Pinheiro
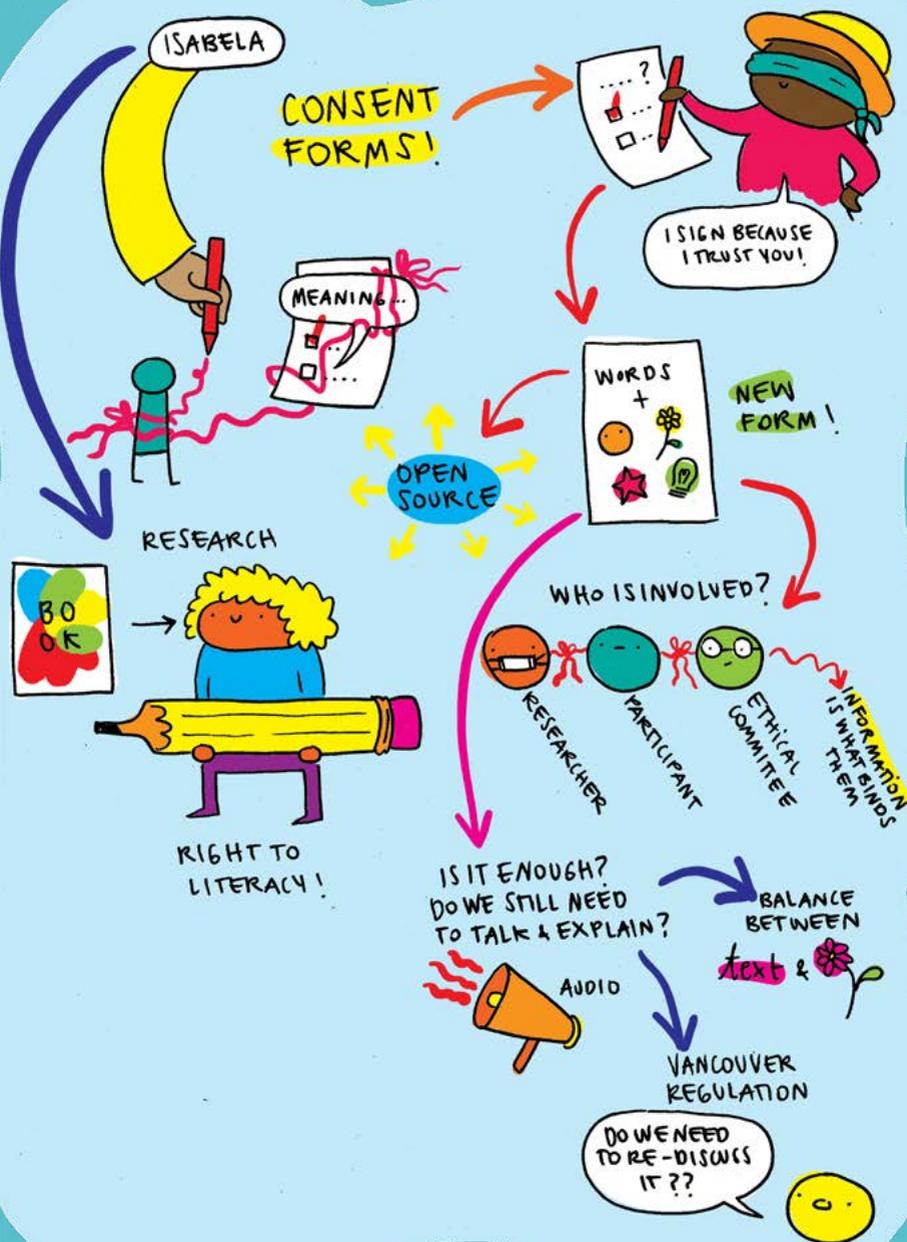
● Within the Sensing for Justice (SensJus) project, we often engaged with participants with low literacy such as peasants and fishers, and we felt that standard, lengthy consent forms were not meaningful for the aim of achieving a really aware participation.

● A WAY FORWARD can be that of illustrating consent forms through drawings or with a video or audio explanation, and take time to discuss the forms with the prospect participants. Such ideas should be tested with Ethical Review Boards.

Audience:

● Can a fully visual consent form replace a textual one? Learning from good experiences such as the consent forms elaborated for low literacy participants.

● We should consider the forms as a tool to initiate a dialogue between the researcher and the participant, as even if the consent form has illustrations this does not ensure full understanding.

Resources:

● The SensJus project page: https://sensingforjustice.webnode.it/

● Bela's portfolio: https://www.belailustradora.com/

● The visual consent forms pilots.
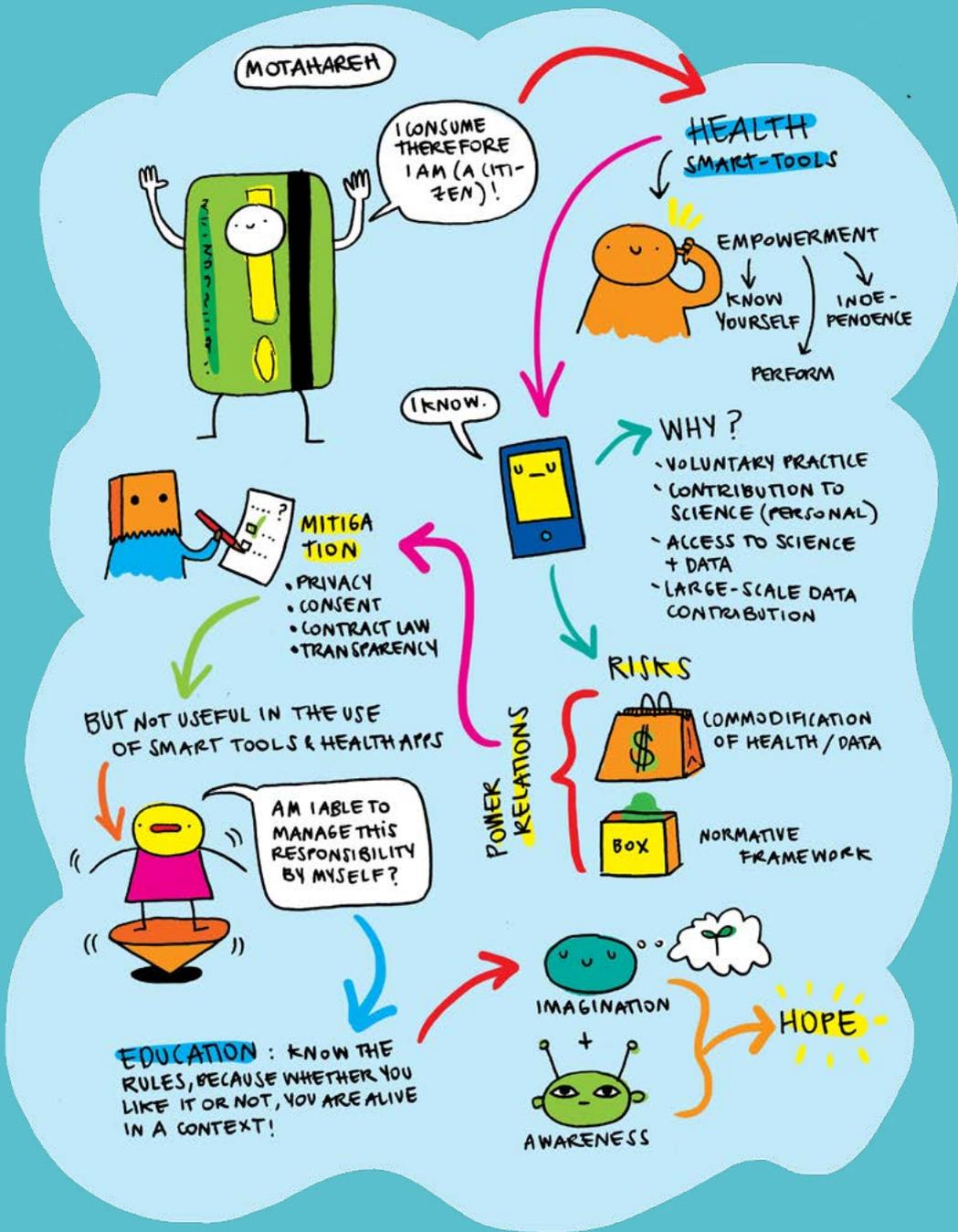
Motahareh Bollon Fathisalout

● Can consumers be viewed as the ultimate form of citizen?

● (Citizen Science) knowledge can turn out to be of an economic value in a neo-capitalistic society where the market determines access to health.

Audience:

● How one defines health changes the lens of analyses. The definition of health by the World Health Organization (WHO) is limited under multiple dimensions. Nonetheless, we also acknowledged that the definition provided by the WHO could be replaced by another one without challenging the framework or the operating rules of neoliberal capitalism.
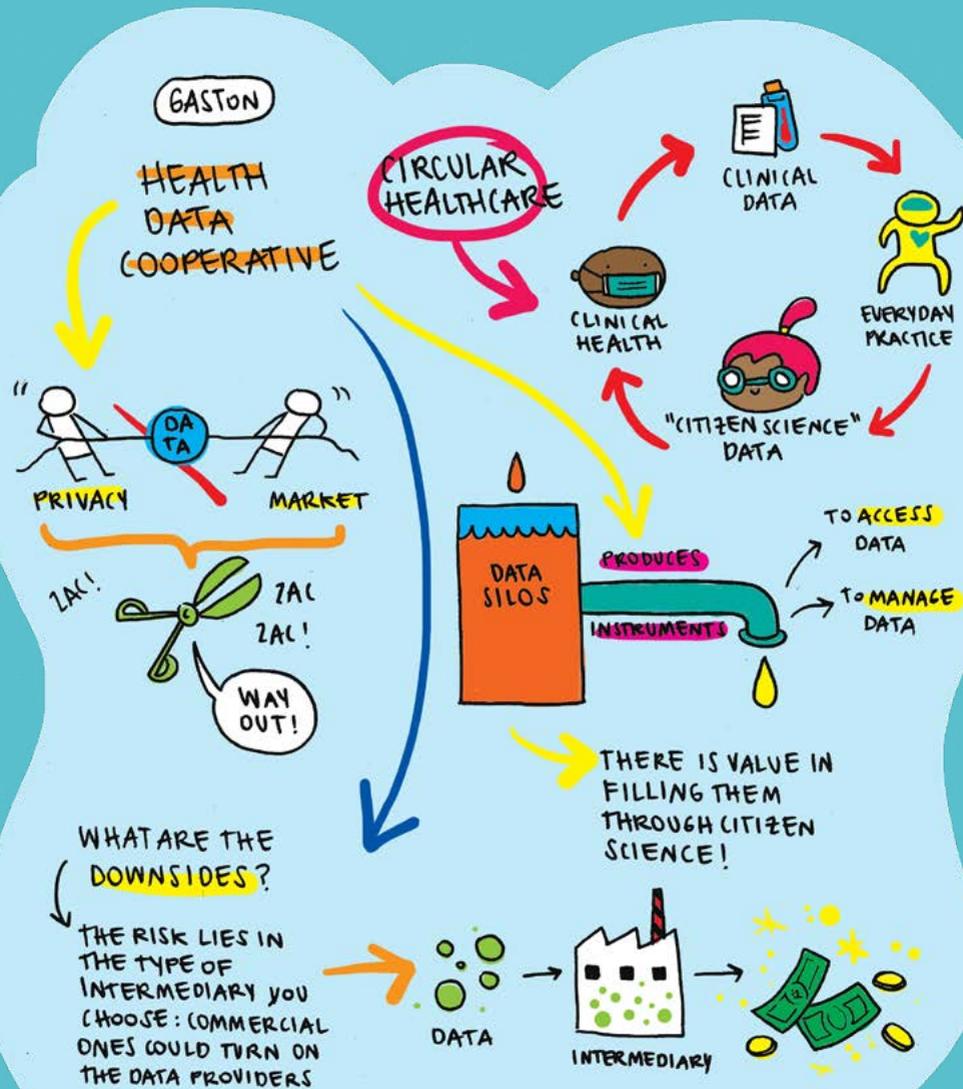
Gaston Remmers

● The Holland Health Data Cooperative as a WAY FORWARD to ensure that a third party actor can negotiate access to health data on behalf of the citizens.
● Balancing the power of tech companies with the leverage and strength of a cooperative.

Audience:
● A discussion on licences for Citizen Science projects matters to understand how we can ensure future access to the initiative's data, beyond the life of an initiative, without hampering intellectual property and privacy concerns.

Resources:
● The Holland Health Data Coop.: http://hhdc.nl/
● The page of SalusCoop, Spain: https://www.salus-scoop.org/
● The page of DigiMI, EU: https://digi.me/
● An initiative on sport data: https://info.sportdata-valley.nl/english/

Bruna De Marchi
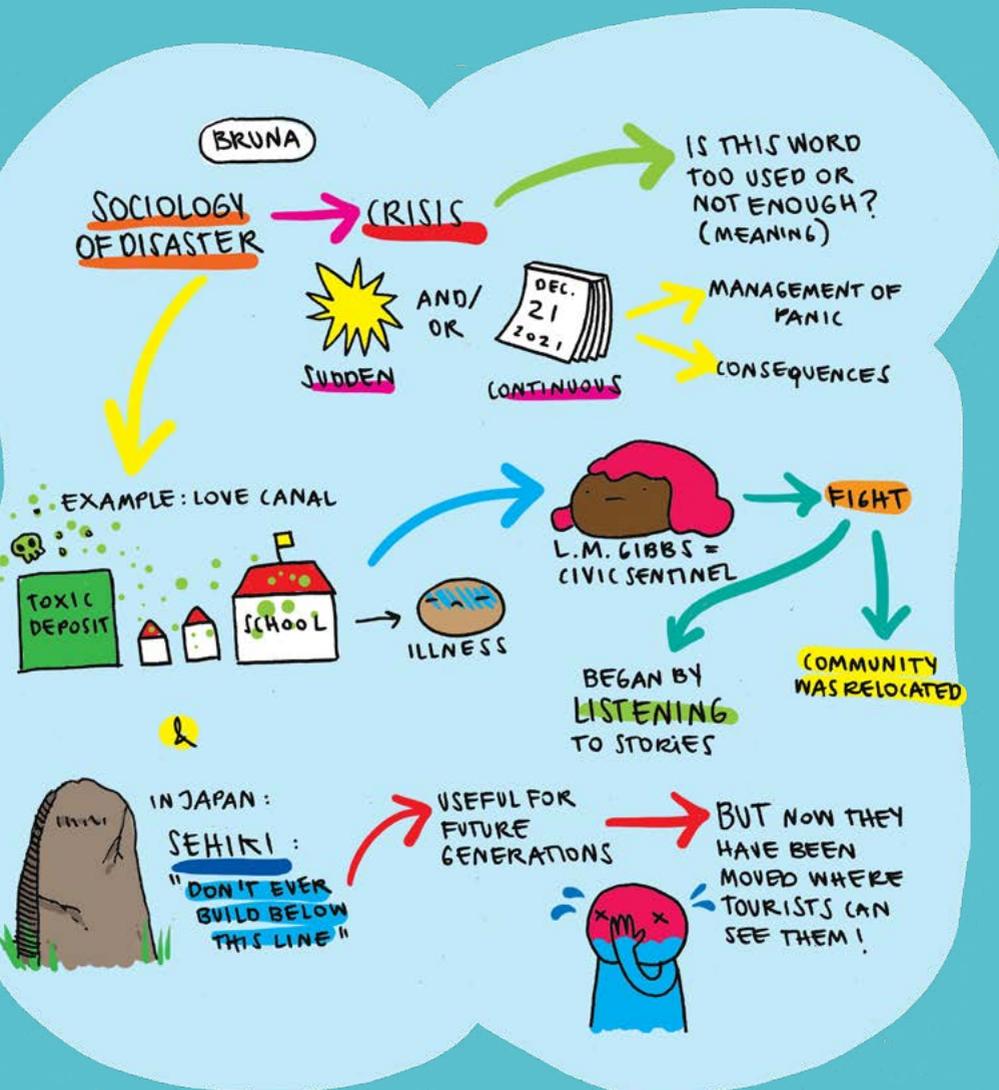
● Maybe we should look at the story of forms of Citizen Science ante litteram, such as the detection of and resistance to the Love Canal contamination; in the Post-Normal Science approach, we need many types of expertise, including that of the sociologist's and the historian's to make sure that also the perspective of those affected is taken into consideration in understanding a crisis.

● Starting from crises as disruptive events not only for public health or the environment but also for the social fabric and for trust. Those in charge - authorities, crisis managers, etc. - tend to concentrate on avoiding the spreading of panic and often downplay the risks associated with a crisis, both immediate and long-term. These attitudes generate even more distrust from the part of the citizens.

Resource:

● Cranor, C.F., Toxic torts: Science, Law and the Possibility of Justice, Cambridge University Press, 2008, on the difficulty to prove environmental and health damage in Court.
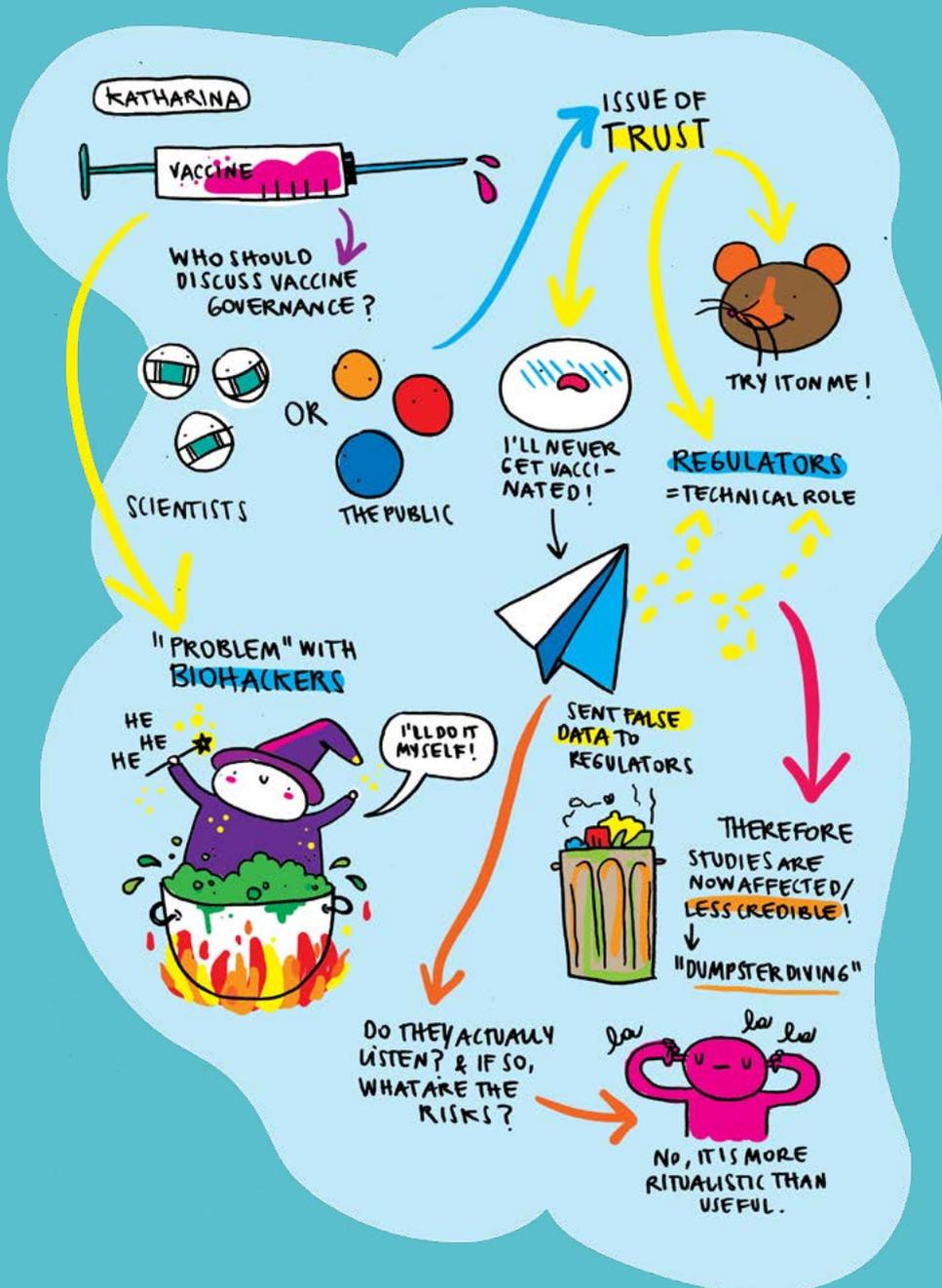
Katharina Paul

● Discussions on vaccinations – as a deeply political and polarized matter – often revolve around what knowledge is relevant.

● The engagement of the public in vaccination evidence historically was not very participatory, mostly including the mere reporting of adverse effects - these are more or less technocratic token practices and dismissed by many formal experts.

● With the advent of Covid-19 vaccines, we saw a new wave of participation on vaccines' research, including a high willingness to participate in trials to contribute to the public good, and cases of what Haklay would term 'Extreme Citizen Science', such as biohacking. But both types of participatory knowledge-making entail risks and arguably speak to the 'dark side' of participation: biohacking and do-it-yourself (DIY) vaccines risk bypassing rigorous testing. Furthermore, registries/platforms to report vaccine side-effects have been misused to report fake data on vaccines implications for human health. This points to potential perils of participation.

● **A future outlook:** despite these risks, Citizen Science Communities of Practices (including Citizen Scientists, formal experts and decision makers/funders) must consider forms of participation to enhance public trust in vaccination. This remains one of the greatest challenges in contemporary public health policy and is somewhat reminiscent of the problem of trust in science in the case of environmental policy and the climate disaster.

Nils Heyen
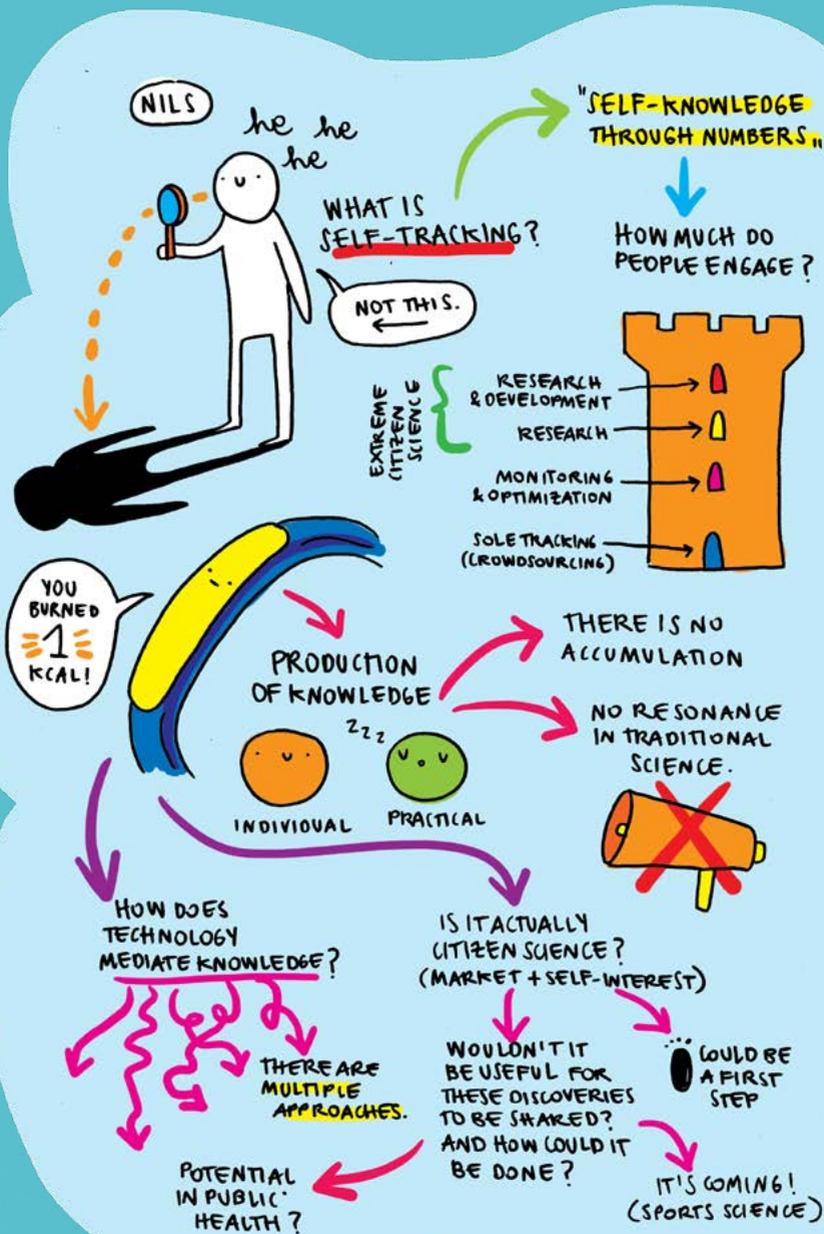
- In health and medicine related fields and in the sociology of medicine, a notion of lay knowledge or lay expertise has long been common, for instance, with regard to patients who have intensively dealt with a chronic disease for many years. Scholars in the sociology of knowledge and expertise within Science (and Technology) Studies have called that 'not-certified' expertise.
- Self-tracking (so far) is basically connected with citizen science in two different ways: one are crowdsourced health research studies, the other the personal research studies and activities of the self-trackers themselves which might be called personal science.
- The knowledge that is produced by doing personal science can be conceptualised as self-expertise.

Audience:
- Can self-tracking be a first step towards Citizen Science?
- What about the mediation of knowledge by technology in self-tracking through digital devices?

Resource:
- The article discussed, published in the journal 'Public Understanding of Science': https://doi.org/10.1177/0963662519888757

Day 2

Sandra De Vries

- The market should not always be regarded as an enemy for Citizen Science but it can actually be useful.
- Experiences such as that of the Water Lab in Delft or of Drinkable Rivers across Europe often uses geo-location data, for example to assess potential effects of climate change on rains.
- As geo-location data are personal data GDPR concerns could hinder this type of data collection which is fundamental for the initiative.

Audience:

- What is the role of market actors in such types of Citizen Science initiatives? So far the private actors mostly have a role only as providers of the tools that the citizens will use but we can imagine a more pervasive engagement, especially as the knowledge generated by Citizen Science initiatives can be of economic value.

Resources:

- The initiatives discussed: https://www.tudelft.nl/citg/over-faculteit/afdelingen/watermanagement/research/waterlab; https://drinkablerivers.org/
- PULSAQUA page: https://www.pulsaqua.com/

Anna Abita
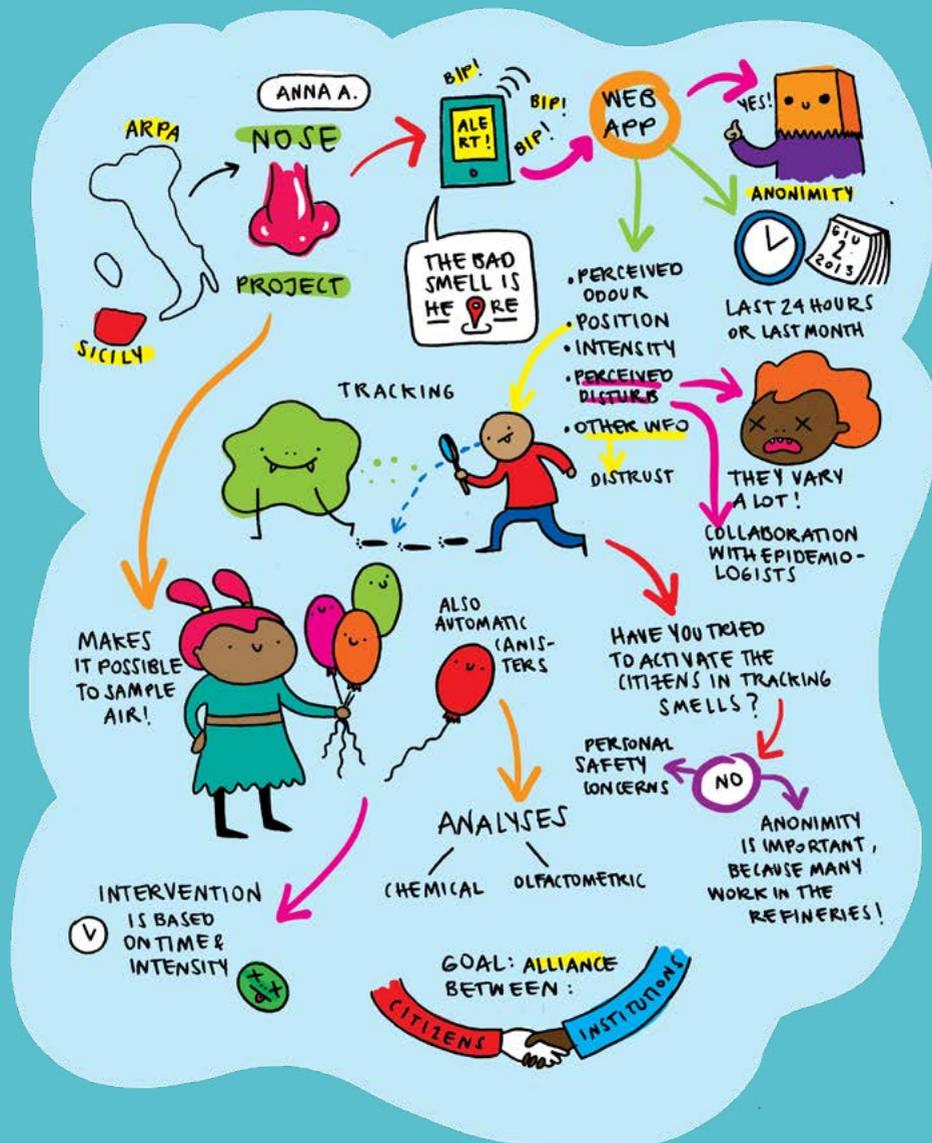
● The experience of the NOSE project realized by the Sicilian Regional Environmental Protection Agency (ARPA) and by the Italian National Research Council (CNR) in Sicily demonstrates the importance for public decision-makers of data contributed by local inhabitants on the perception of odour and associated ailments, which may eventually mitigate the distrust of citizens towards authorities.

● Citizens can report through a free app the type of odour they detect, its intensity and the perceived health consequences that will then be read together with institutional data to guide interventions on odour pollution.

● The data collected – even if geo-localized – are anonymous to ensure that no personal data is processed, however GDPR concerns hindered the possibility of exploring pilots with schools.

Resource:

● The page of the NOSE project: https://www.arpa.sicilia.it/temi-ambientali/aria/nose-network-for-odour-sensitivity/
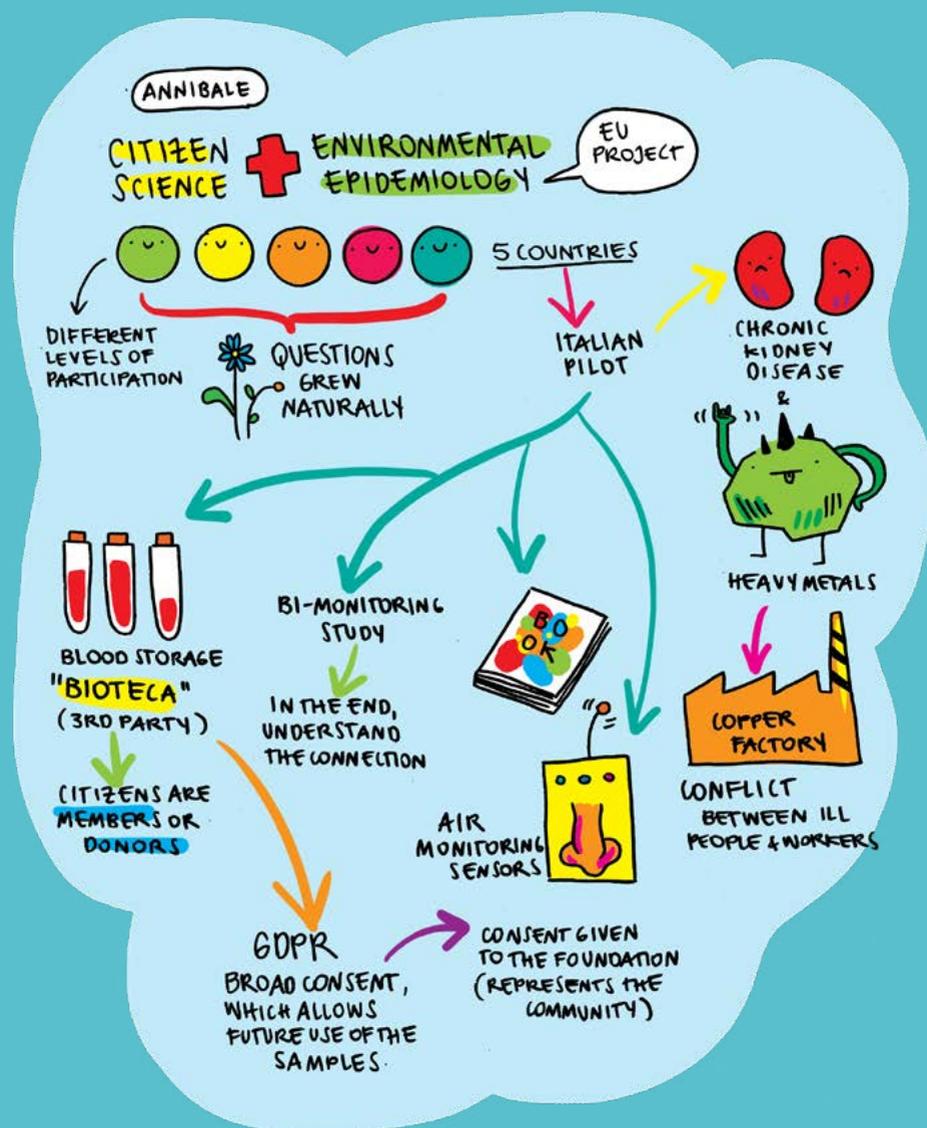
Annibale Biggeri & Bruna De Marchi

● The experience of Cities-Health, an Horizon2020 funded European project, is based on participatory epidemiology pilot-studies, spanning from contributory Citizen Science to co-creation. In the Italian case, a 'bio-library' (a term and a concept different from that of bio-bank) is being set up.

Future use/processing of such materials and data is subject to authorisation from the Foundation.

● The research project is taking place - particularly in Italy, Garfagnana, Tuscany - in a context where there is already an engaged community, with many residents being aware of environmental health problems (stemming from the possible correlation between kidney disease and the local copper factory). Many residents are supporting the research and willing to fight for their health and environment, whilst others, in particular among those working in the factory, oppose such research.

● In a context of Post-Normal Science, participatory epidemiology can become a space of negotiation - not necessarily agreement - between environmental groups, scientists, public institutions and administrators, and the local population.

Resources:

● The EU project page: https://citieshealth.eu/
● A complementary air quality monitoring initiative discussed: https://www.ariadiricerca.it/

Antonella Ficorilli

● In (Health) Citizen Science the participants maintain their traditional role as researched subjects but also acquire a new role as researchers themselves: for this second role, currently there is a lack of legal recognition.

● The traditional ethical requirements of dignity, autonomy, privacy and a fair data management should be adapted to this new role of the citizen scientists, but not always Ethical Review Boards are ready to recognize the specific features and needs of research on Citizen Science and with the citizen scientists.

Audience:

● We should stop assuming symmetry and equality among people, recognizing the diversity of participation is a first step for equity in Citizen Science.

Resource:

● Investigating the Process of Ethical Approval in Citizen Science Research: The Case of Public Health: https://jcom.sissa.it/archive/20/06/JCOM_2006_2021_A04

Karin Van Leersum

● The experience of the TOPFIT Citizenlab in Twente as an illustrative example for the challenges and adaptation needed as a result of the GDPR: a place where people interested in Citizen Science can come to join, talk about what matters most in their life and needs and wishes for improvement and receive advice also in terms of ethical and lawful (health) data management.

● The idea of a more accessible informed consent under the form of a video to make it for migrant participants aware consenting easier; also a dynamic informed consent is needed for a research project that does not foresee at its start all its possible developments and research activities.

● Various pilots including a study with people with type 2 diabetes, one for migrants with dementia and one to work together with a citizen to do research into their their neighbourhood and make it more inclusive for the elderly.

Resource:
● The TOPFIT Citizenlab page: https://www.topfitcitizenlab.nl/

Huma Shah

● The interrelation between the GDPR and health tracking apps can be unveiled through a game showing how long it takes for you to detect and disable a cookie tracker.
● Several examples of (UK) websites for patients where no informed consent is given, which value more their economic interests than users' privacy.
● Citizen Science in this context should lobby to improve compliance with GDPR regulations.

Resources:
● The cookies game: https://cookieconsentspeed.run/
● The CSI COP project: http://csi-cop.eu/
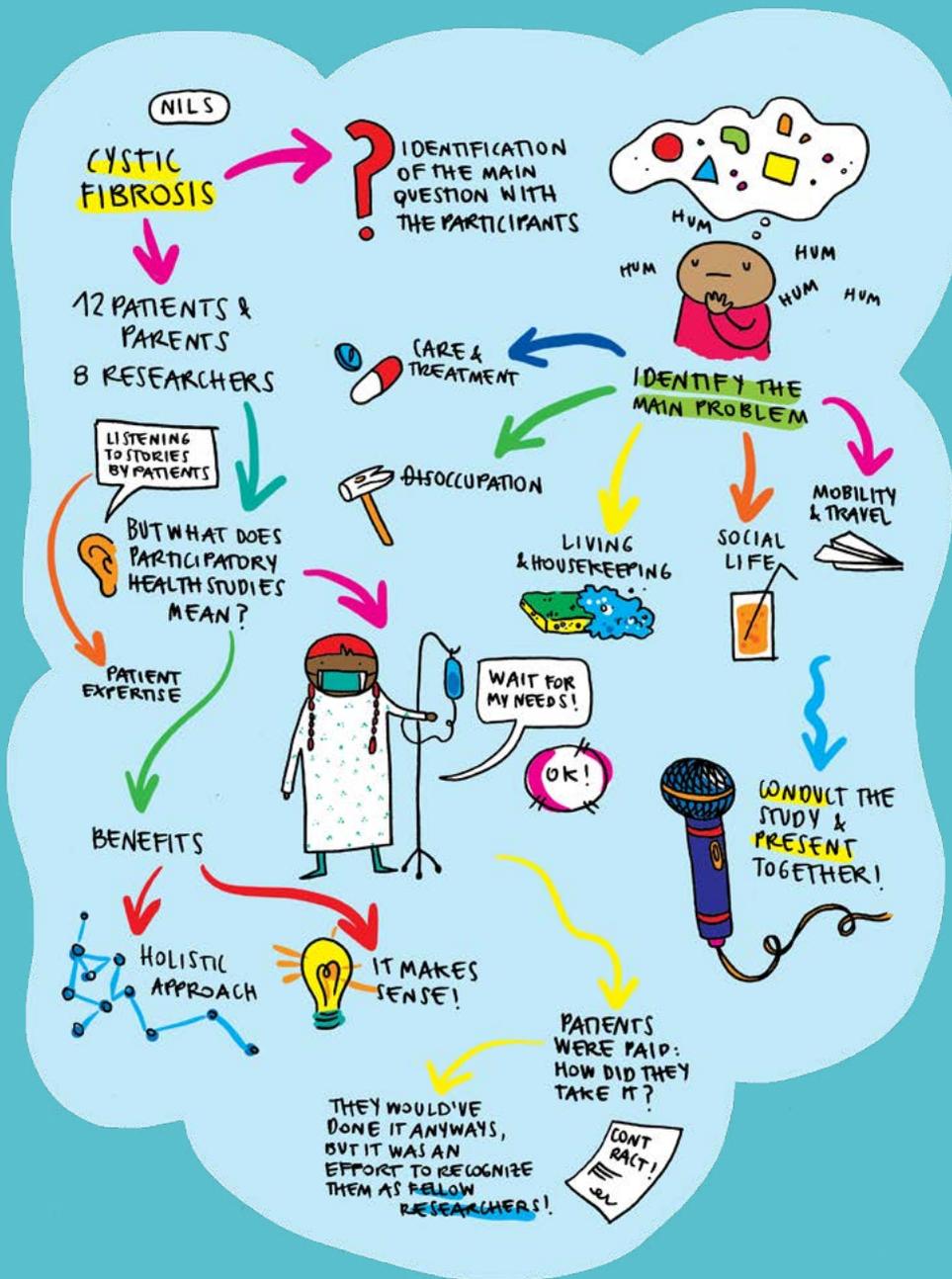
Nils Heyen

● The Patient Science project as an example of working with rare disease patients, such as cystic fibrosis, seen as co-researchers and therefore rewarded with a salary similar to that of a research assistant and asking them to sign a contract of collaboration, not an informed consent: a WAY FORWARD?

● The participatory research inspected the everyday struggles of cystic fibrosis patients through an in-depth survey and provided an evidence base that was absent: benefits exist on the participant, the socio-economic and the scientific dimension.

● Citizen Science with patients with chronic diseases requires recognition of different implications including their high expertise and the consideration of their high motivation; challenges derive from the low physical resilience of the patients and the high responsibility that both patients and researchers share.

Resource:
● The initiative page: https://www.buergerschaffenwissen.de/projekt/patient-science-patienten-schaffen-wissen

Gaston Remmers & Sabine Wildevuur

● The recognition of the distinctive features of Citizen Science in the health domain stimulated the launch of a working group dedicated to this theme within the European Citizen Science Association (ECSA).
● The working group launched a survey to grasp from the Citizen Science community how Health Citizen Science is perceived and what are its drives and struggles.

Resources:
● The working group page: https://ecsa.citizen-science.net/working-groups/citizen-science-for-health/
● Link to the working group survey: https://forms.office.com/r/Q7U9ctbLNC
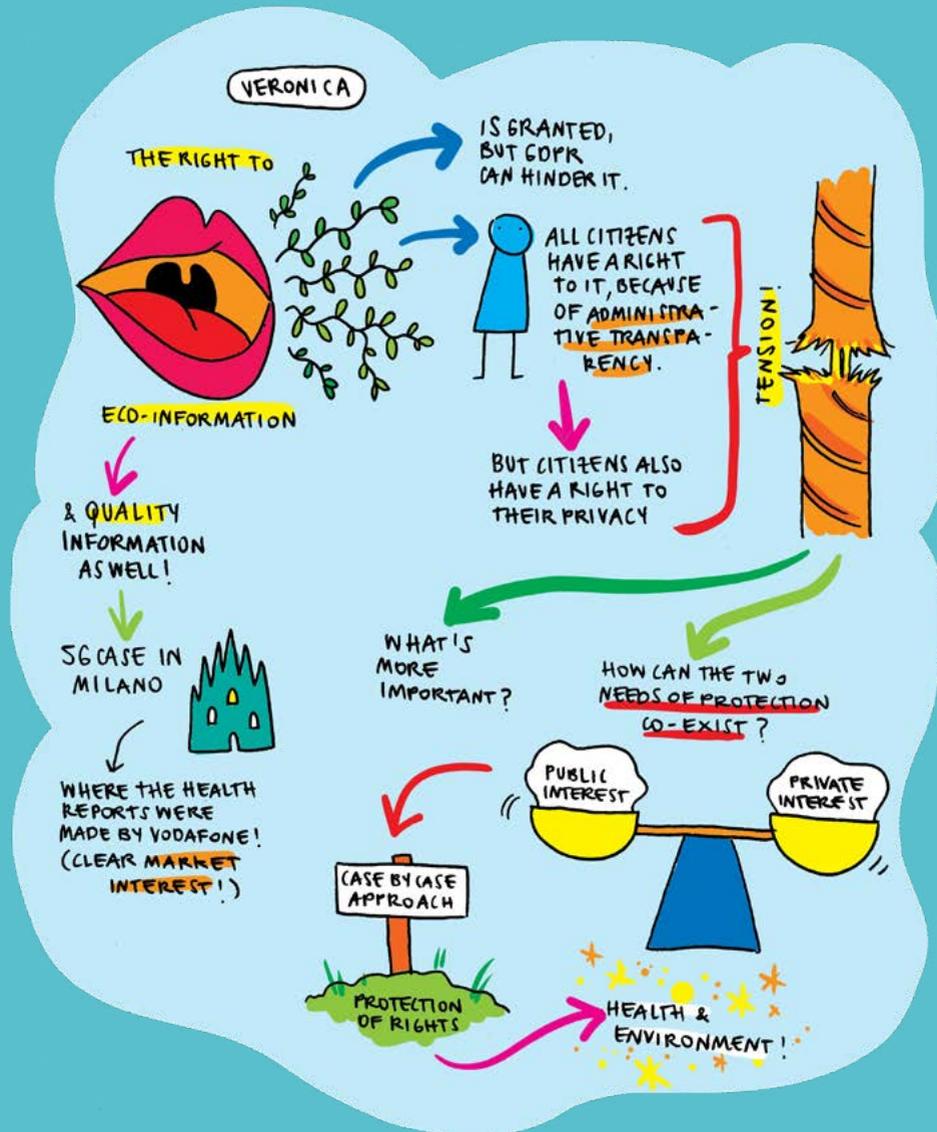
Veronica Dini

- Italian Law for the balancing of transparency and openness in the provision of (environmental) health information to the public is a good example of tensions between interests to secrecy and interests to generalized access to information.
- A transition from 'the need to know' to 'the right to know' on matter affecting health and the environment: A WAY FORWARD could be 'a civic right to contribute to environmental (health) information'?
- The example of 5G developments in Milan and its impact on public health as a testbed for exploring the tensions between state secrecy, companies' intellectual property and citizens desire to access information.

FEMINIST

WHAT DO THEY ACTUALLY TELL?

ARE THERE ANY "BIASES"?

NOT ONLY PROTECTION, ALSO DIFFERENT PERSPECTIVE!

WHO IS REPRESENTED?

DATA

FOUNDATION

ECSA

DATA CONTROLLER/ INTERMEDIARY

SMALL PROJECTS ONLY MANAGE SMALL AMOUNTS OF DATA

ACTUALLY NEED COUNSELING

RISK: DEPENDING ON INSTITUTIONS

NON-GOVERNATIVE THIRD PARTY

EUROPEAN STATISTICAL BUREAU

? QUESTIONS

TIME

PLACE

EVEN FOR FOUNDERS!

ALL SETTINGS & VARIABLES ARE VALUABLE & ONLY NEED TO BE COMBINED TO MAKE THEM WORK!

METHOD

DE-COLONIZATION NEEDED!

SITE-SPECIFIC & COMMUNITY SPECIFIC

PARTICIPANTS

RESEARCHER + CITIZEN

ENGAGEMENT STRATEGIES

FINAL CONVERSATION

PATIENT

RESEARCHER

DO WE EVEN NEED THEM WHEN WE WORK TOGETHER?

DEPENDS ON ROLES, NOT ON PEOPLE

CONSENT FORM

EITHER WAY, CANNOT BE AVOIDED.

CONTRACT

TOOLBOX MAP ROOM...

Takeaways

● Overall, we need to adopt the epistemic diversity and the multiform nature of engagement strategies and of participatory desires as a starting point to analyse the possible implications of the GDPR for (Environmental) Health Citizen Science, for example exploring how indigenous cultures deal with the problem of balancing access and confidentiality to the data of their community.

● In order to ensure informed consent of (Citizen) Science participants we should strive for dynamic forms of informed consent, possibly using different communication forms such as visuals, audio and video clips as well as ensuring that the consent phase is the end of a process of understanding.

● The cooperative model based on intermediaries (for example a foundation) as data stewards and guarantors of the citizen scientists' privacy vis-à-vis researchers, institutional actors and - when admissible - market actors can ensure access to relevant research data while preserving the confidentiality of the information and respect of the GDPR.

● There are grey zones where GDPR compliance for Citizen Science is more difficult, especially for very local, spontaneous, small-scale and low-budget initiatives that are not supported by a public agency nor linked with an academic institution and which may find very hard to identify a data controller, conduct a Data Protection Impact Assessment (DPIA) and bear the responsibility for eventual GDPR breaches.
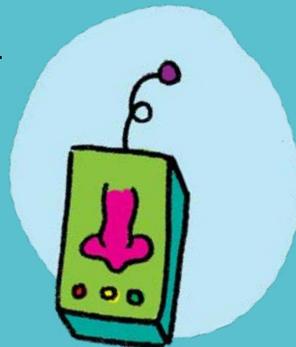
● For Citizen Science initiatives struggling to comply with the GDPR or for which GDPR compliance may be a hindrance to their operations, associations such as ECSA or organizations involved in research such as the European Statistical Bureau could provide support; however, this may create a dependency of the initiative on these organizations. An alternative could be providing peer trainings in the form of Q&A (Questions & Answers) platforms or video pills on steps to ensure compliance with the GDPR, and the possibility to establish legal clinics within universities where students can advise citizen scientists on GDPR requirements and actions to be taken to align the initiative with the GDPR.

● All these reflections and conclusions apply differently depending on how you define Citizen Science: during this workshop we refrained from agreeing on a sole definition of Citizen Science but we explored instances of more institutionalized, 'invited' Citizen Science to more spontaneous, 'uninvited' Citizen Science which has been called 'extreme' [Haklay] or 'reactive' [Berti Suman]. We concluded that the multiform nature of 'Citizen Sciences' cannot be captured in a definition.

Bios

Robin Pierce is on the faculty at Tilburg Law School in The Netherlands. Her work addresses the translational challenges for the development and integration of emerging technology for clinical and health applications. Applying legal, ethical, and policy analysis, her recent work has examined translational challenges in therapeutic robotics, AI for diagnosis, prognosis, and resource allocation, and data protection and privacy issues in emerging health technologies. She is a lead on the H2020 project on Citizen Science and the GDPR. She has served on numerous research ethics committees, including Harvard Medical School hospitals, Harvard University, and Harvard School of Public Health. She serves on the editorial boards of the Journal of Bioethical Inquiry and Journal of Technology Regulation. She leads the Health Law, Ethics, and Technology initiative at Tilburg Institute for Law, Markets, Technology and Society at Tilburg Law School.

Huma Shah is the Director of Science leading an eleven-partner international team on an EU Horizon2020 funded citizen science research and innovation project, CSI-COP: https://cordis.europa.eu/project/id/873169. Huma has a PhD in 'Deception-detection and Machine Intelligence in Practical Turing tests' gained from Reading University UK. She has organised public Turing test experiments, including Turing100in2012 at Bletchley Park, an event which gained the London2012 Inspire Mark for Education: https://www.reading.ac.uk/news-archive/press-releases/pr445524.html. Huma is lead author or co-author of over thirty publications, including in Q1 journals and conference proceedings. She co-authored 'Turing's Imitation Game: Conversations with the Unknown', published by Cambridge University Press in September 2016

Nils Heyen is a sociologist and has been a senior researcher and a project manager in the Competence Center Emerging Technologies at Fraunhofer Institute for Systems and Innovation Research (ISI) in Karlsruhe, Germany, since 2011. Since 2020, he is Coordinator for Technology Assessment at Fraunhofer ISI. He studied sociology and psychology at the Universities of Bielefeld, Hanover and Edmonton (Canada) and did his postgraduate studies at the Institute for Science and Technology Studies (IWT) at Bielefeld University. His main research areas are emerging technolo-gies and social innovations in medicine and health care, the science-society relation-ship, concepts of technology assessment, and the sociology of knowledge, professions and medicine.

Karin Van Leersum When I became a Technical Medic, I had the feeling there was more to learn and take into account when doing research.

I was always interested in the ethics and philosophy of technology, therefore I started and finished a second master in Philosophy of Science, Technology and Society. This background gave me the ability to work as a PhD at the Family Medicine department of Maastricht University. The aim of my PhD project was to develop a tool to assist with communication about the things that matter most in care and life, specifically made for clients in need of long-term care and their professionals. This tool was designed, developed and evaluated together with all possible end-users. Currently, I am starting as a Postdoc at the department of Science, Technology, and Policy Studies at the University of Twente: https://people.utwente.nl/c.m.vanleersum. As part of the TOPFIT CitienScience research team I will mainly investigate the influences of eHealth on the society, for example the patient doctor relationships or the influences of eHealth on the elderly society, and how to perform Citizen Science.

Katharina Paul obtained her PhD at the University of Amsterdam in 2009. Following three years as assistant professor at Erasmus University Rotterdam she joined the University of Vienna in 2013 with a Lise Meitner Grant (FWF) and a subsequent Top Citizen Science Grant (FWF). She teaches comparative policy analysis and qualitative methods at the Department of Political Science and currently holds an Elise Richter Fellowship (FWF). In addition, she leads a work package in a H2020 research project on the role of epidemiological data in global health diplomacy. Her current research focuses on vaccination policy and the role of evidence in policymaking, including evidentiary practices in citizen science.

Motahareh Fathisalout is Associate Professor of Law at the Law Faculty of Savoie Mont Blanc

University, where she focuses on studying the renewal of civil law and especially the law of obligations under the influence of information and communication technologies from a critical perspective. In particular, she seeks to analyse the political, philosophical and economic determinations of legal discourses. She has co-edited with Anna Berti Suman a book entitled "Legal, Social and Ethical Perspectives on Health and Technology". She is a member of the editorial board of the journal Jurisprudence - Revue Critique.

Anna Berti Suman is a Marie Skłodowska-Curie Fellow and former Dutch Research Council Fellow at the European Commission Joint Research Centre. Through the project "SensJus", Anna is performing research on the potential of civic monitoring as a source of evidence for environmental litigation and as a tool to foster environmental mediation. Anna obtained her PhD from Tilburg University, Law School. Her PhD project aimed at investigating how Citizen Sensing, grassroots-driven monitoring initiatives based on sensor technology, influences the governance of environmental health risk and how the practice can be integrated with institutional models of risk governance through its social and policy uptake.

Carlo Botrugno graduated in Legal Sciences (2005) and in Social Work (2012) at the University of Bologna; he holds a Master in Law (2008), and a PhD in Law and New Technologies (2016) from University of Bologna. Currently, he is a postdoctoral researcher at the Department of Legal Sciences of Florence University. He is founder and co-coordinator of the Research Unit on Everyday Bioethics and Ethics of Science (RUEBES), which is part of the L'Altro Diritto Interuniversity Research Centre. He has been postdoctoral fellow at the Institute of Health Care Ethics

of Slovak Medical University (SZU); and visiting PhD student at: Centre for Social Studies (CES) of Coimbra University; Porto Alegre Clinicas Hospital (HCPA); Porto Alegre Uniritter dos Reis University. His main research interests are related to: biolaw, bioethics and medical ethics; ITs and technological innovation in healthcare; public policy and health law; human rights, discrimination and citizenship; migration, vulnerability and social determinants of health.

Alice Toietta is a freelance illustrator and graphic designer who currently focuses her work on live drawing for conferences and webinars. She is a passionate environmental activist, and recently realized a comic book on civic monitoring / active citizenship in collaboration with Dr. Anna Berti Suman. Her previous work experience mainly consisted in big-size decorative panels and wallpieces, which she would paint on walls and furniture alike. This work experience taught her much about the work ethics and routine a creative professional must have. She graduated in 2017 from the Free University of Bolzano, Faculty of Design and Arts.
https://www.instagram.com/aelisir.illustration/

Annibale Biggeri is Professor of Medical Statistics at the University of Florence, Italy. He is President of the non-profit social enterprise Società per l'Epidemiologia e la Prevenzione "Giulio A. Maccacaro", Milan, Italy. He worked as cancer epidemiologists and his scientific interests focused on statistical methods in epidemiology, spatial statistics and disease mapping. He contributed to the research on health and environmental hazards and in particular on the evaluation of high risk areas. His most recent research addresses health effects of environmental problems or environmental disasters in populations and exploits

participatory approaches, multi- / trans-disciplinary and citizen science.

Dana Mahr https://www.unige.ch/ic/equipe/dana-mahr/

Bruna De Marchi is a sociologist currently associated with SVT (Centre for the Study of the Science and the Humanities) at the University of Bergen, Norway https://www.uib.no/en/persons/Bruna.De.Marchi She is also affiliated with the non-profit social enterprise Società per l'Epidemiologia e la Prevenzione "Giulio A. Maccacaro", Milan, Italy. Her main professional interests are in the field of health and environmental hazards and risks, with a focus on organizational aspects, risk perception, communication and governance. Her most recent research addresses health and environmental problems in areas exposed to pollution from industrial installations and is grounded on extended collaboration between professional investigators from different background and citizen scientists.

Gaston Remmers https://joinus4health.eu/people/gaston-remmers/

Veronica Dini https://www.veronicadini.com/

Sabine Wildevuur https://people.utwente.nl/sabine.wildevuur

Carsten Lyng Obel https://pure.au.dk/portal/en/persons/carsten-obel(8218dd6b-87e3-4f8f-a-a42-880be6a62484).html

Antonella Ficorilli is a bioethicist that graduated in Philosophy. She held a PhD in Bioethics at

Bologna University in 2009 and a Master's Degree in Practical Ethics and Bioethics at Sapienza University of Rome in 2005 (Italy). She has conducted research activities at Oxford University and other universities and scientific institutions. She is currently participating in the Cities-Health H2020 project as an external collaborator for the non-profit social enterprise Società per l'Epidemiologia e la Prevenzione "Giulio A. Maccacaro", Milan, Italy. Her recent research interests are primarily in the field of research ethics, with a focus on citizen science and participatory epidemiological studies. A specific field of her interest regards the ethical and regulatory issues related to biobanking in biomedical and epidemiological research.

Sandra de Vries founded PULSAQUA (https://www.pulsaqua.com/) little more then 2,5 years ago. With a civil engineering background and a specialization in Water Resources Management, she focusses on applying citizen science to the field of water, climate, and environmental issues. PULSAQUA advises on Citizen Science use, creates Citizen Science (monitoring) projects and delivers environmental impact assessments together with citizen scientists. We help NGO's, government agencies and industries to track and monitor specific desired changes that society needs to go through, together with that same society. With PULSAQUA she aims to add to reaching the Sustainable Development Goals. Sandra also holds a guest researcher position at the Delft University of Technology and is partner of the TU Delft citizen science platform WaterLab (http://www.onderzoekwater.nl/).

Torben Sisgaard https://pure.au.dk/portal/en/persons/torben-sigsgaard(5d7f5dc8-00a-48ba-9467-a93703b015b7).html

Anna Abita is a chemical manager of ARPA Sicilia, involved in environmental monitoring and control activities since 1992.Her areas of work include the control of waste treatment plants, contaminated sites, quality of inland waters, and air quality. She is the Director of the Air Quality Complex Operating Unit, responsible for managing the regional monitoring network of Sicily, and conducting annually, the analyses of related monitoring data. She has contributed to the development of the Regional Air Quality Protection Plan and to the periodic updates of the Regional Emission Inventory. She collaborates with CNR-ISAC for the development of NOSE project.

Bela Pinheiro is an illustrator based in Brazil, Rio de Janeiro, passionate about visual storytelling for children and adults. She desires to communicate the same enchantment she felt when she discovered the picture books as a child. Bela has also a degree in Law from the University of Rio de Janeiro (UERJ). For her Master degree on Theory and Philosophy of Law at the same institution, she's currently studying the relevance of children's books illustrations on the context of Literacy as a fundamental human right. For further information: belailustradora@gmail.com https://en.belailustradora.com/
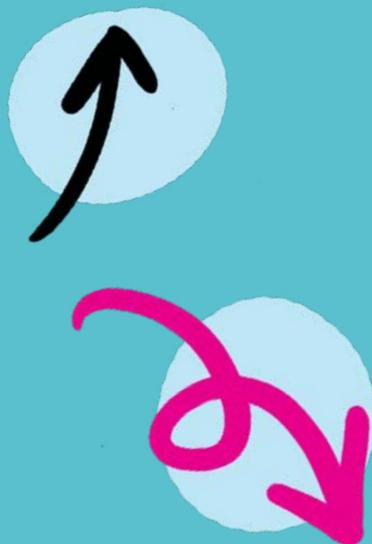
Visual Forms

This resource is in evolution.
For the the latest verions of this form check:
https://drive.google.com/drive/u/0/folders/1iK-MlVszDXI4s15DjVy_8gS1VkekAKnUq

SensJus Visual Participant Information Sheet

Project title: *SensJus* - 'Sensing for Justice'. Marie Skłodowska-Curie grant n. 891513.

Host institution: The European Commission Joint Research Centre (JRC), Digital Economy Unit, Italy. The JRC is the science and knowledge service that provides independent scientific advice and support to European Union (EU) policy.

Researchers: Dr Anna Berti Suman and Dr Sven Schade. See
https://sensingforjustice.webnode.it/about-us/

Visual summary: a 'civic sentinel' monitoring radiation in the air around a factory

Introduction

My name is Anna Berti Suman. I am a researcher at the European Commission JRC, Italy, together with Dr Sven Schade. Our project is called **SensJus** ('Sensing for Justice'). You can find out more about the project here:
https://sensingforjustice.webnode.it/.
The project is funded by the EU.

Our research focuses on **how people use monitoring technologies or their senses to find evidence** of environmental damage and use this evidence in **environmental litigation or mediation**. We call these practices '**citizen sensing**'. We explore whether and how citizen sensing can be **an effective new way** to find evidence about environmental wrongdoing.

Environmental litigation = court cases against companies or public bodies that harm the environment.
Mediation = ways to address the problem outside the court.

1

Invitation

You are invited to take part in **our research on citizen sensing** under the SensJus project, as an expert or as a participant. Before you decide, you should **understand why** the research is done and what it will involve. Please take time to **read** the following information carefully and **discuss** it with others if you want. If there is anything that is not clear or if you would like more information, please **ask us**.

What is the purpose of our research?

Imagine a **fisherwoman** wants to claim that a river is polluted and she takes a sample as **evidence**. We want to find out whether and to what extent **citizen sensing can be used as a source of evidence in environmental litigation** and **as a resource to facilitate mediation of an environmental problem**.

Why are we inviting you to take part?

We are inviting you to take part in this research because:
- you are an **expert** on citizen sensing, and/or
- you **know about** a citizen sensing initiative due to your job, and/or
- you are **taking part** or you took part in a citizen sensing initiative.

2

SensJus

Do you have to take part?

No. Your participation is **entirely voluntary**. You decide whether or not to take part. If you take part, you can still **withdraw at any time** and without giving a reason.

If you decide to take part, what do you have to do?
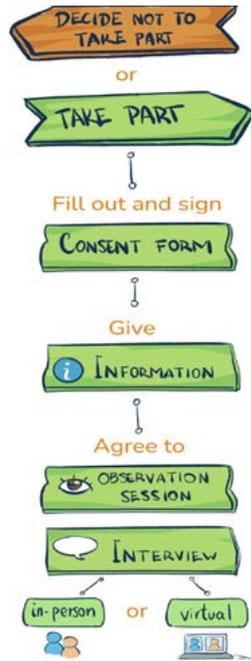
- We will ask you to fill out and sign a **consent form**.

- Right after, we will ask you for **some background information** about your involvement in or experience of citizen sensing, in order to decide whether to proceed with an interview and/or observation session.

- We will invite you for an in-person or virtual **interview** about your knowledge or experience of engaging in/with a citizen sensing initiative. We might **take notes** and (if you agree) **record** the interview. It will take around 30 minutes or possibly more (depending on your availability).

- If you agree, we might also **follow** you while you run a citizen sensing initiative (observation). This would be in addition to or instead of interviewing you. We might **take notes** and **record** what we observe (for example by taking photographs). But only if all participants agree.

3

SensJus

Why does your contribution matter to us?

You will actively help us to **better understand** the role and impact of citizen sensing on court cases and on mediation, as a means to **identify and address environmental harm**.

Are there any disadvantages or risks in taking part?

Not really. We **do not expect any risks** to you if you take part in this research. If you fully voluntarily choose to share sensitive and confidential information with us, we will **ensure it is protected.**

If our questions or any part of our research cause you any distress (e.g., re-experiencing previous suffering or forms of 'eco-anxiety'), please let us know via the email address at the end of the form.

Will your personal information be kept confidential?

All personal information we collect about you during the course of the research will be kept **strictly confidential**. We will collect **only information needed** for the purpose of our research. You will not be identified in any publications or presentations. If you like, though, **you can give your consent to be named or identified in this study**. We will discuss the options together. You can express your preferences in the **consent form** that we will give you.

We will store your personal data **for the time strictly needed** (not exceeding two years from the collection) in electronic format in a safe virtual space owned by the JRC. Anonymized results from our interviews and observations will be stored to ensure long-term preservation of the research, following the **FAIR Data Principles** (Findable, Accessible, Interoperable, and Reusable scientific data).

What will happen to the results of the research?

The **results** will form part of the SensJus project and its findings. These will be **shared through openly accessible publications and presentations**. If you would like to, just **let us know** and **we will inform you about these results** through the communication channel of your choice.


4

SensJus

What procedure will we follow for processing personal data?

Any personal data you voluntarily share with us will be processed in accordance with EU data protection rules, namely **EU Regulation 2018/1725** on the protection of natural persons with regard to the processing of personal data by EU bodies.

This regulation aligns data processing by EU bodies with the guarantees of the **European General Data Protection Regulation** (GDPR). Also, the data protection officer at the JRC will keep **records of our data processing activities** for this project. We can share details of this with you if you want.
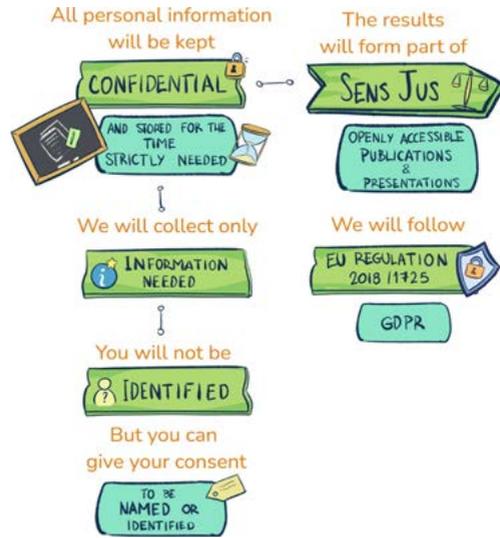
Contact details

If you have any questions or concerns regarding your participation in this research, please contact Anna Berti Suman at
Anna.BERTI-SUMAN@ec.europa.eu.

SensJus - Sensing for Justice
Participant Information Sheet

SensJus - Sensing for Justice
Visual Consent Form
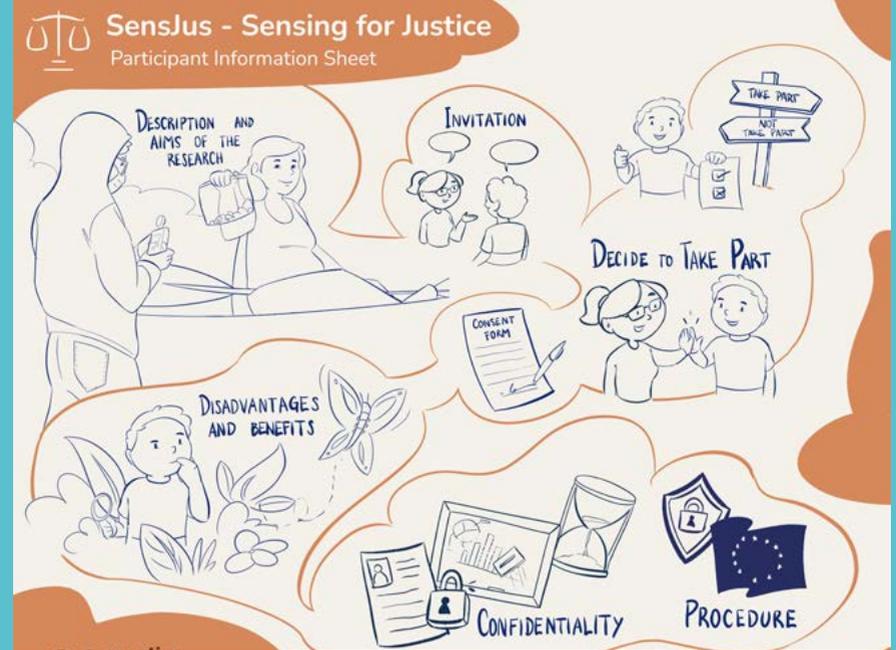
SensJus

SensJus Visual Consent Form

**Project title:** *SensJus* - 'Sensing for Justice', https://sensingforjustice.webnode.it/

Host institution: The European Commission Joint Research Centre, Digital Economy Unit, Italy

Researchers: Dr Anna Berti Suman and
Dr Sven Schade. See
https://sensingforjustice.webnode.it/about-us/

With this form, you can choose whether to take part in this study or not.

Before you make that decision, the researchers will give you an **information sheet** to read. If you have any questions about it, please ask the researchers before you decide.

AGREE

TAKE PART

READ

DISAGREE

.
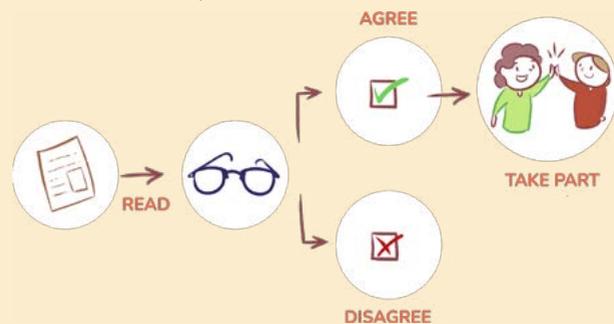
Thank you for considering taking part in this research.

1

SensJus

1. I confirm that I have read and understood the **information sheet** for this research. I have also received sufficient information on how the Joint Research Centre will process and protect my personal data. I have had enough time to consider the information, ask questions and have them answered satisfactorily.

2. I understand that my participation is **voluntary**. And I am **free to withdraw at any time**. This would not cause any penalties for me and I would not have to explain why.

3. I understand that any information I give may be used in **future publications or presentations** about SensJus. And that this information may be communicated to others. This can only happen for scientific purposes. And it must comply with **scientific ethical standards**.

Scientific ethical standards are agreed ways that scientists should behave, in their job. They should not act in a way that harms the interests of other people, in any way.

4. I am aware that any personal data that I voluntarily share with the researchers will be processed following the European Union (EU) rules on the **protection of natural persons** with regard to the processing of personal data by EU bodies. These rules grant me the following rights:
- I can access my personal data at any time;
- I can ask that the researchers rectify any mistakes;
- I can demand that the researchers delete my data;
- I can expect that the researchers only process my data in the ways described above;
- I can object if the researchers do not do this.

5. If I agree to being interviewed or observed by the researchers, I will tell them whether or not they can use any recording they make of it.
I understand that any recording will be used only as an aid for the researchers or for communication activities strictly related to the research.

2

SensJus

6. Encircle the answer that applies to you:

a. I **agree to take part** in the research;

b. I **do not want** to take part in the research;

c. I want to **leave** the study. But the researchers can still **use the data** they collected so far;

d. I want to **leave** the study. And I want the researchers to remove **all my data** that they have collected so far.

7. If you answered "a", please **encircle the answer that applies to you**:

a. I prefer to be referred to as '**anonymous**' and to have my **role** described as ....
(add a description of your role, e.g., fisherwoman)

**b.** I prefer to be referred to as '**anonymous**';

c. I am happy for you to **mention my name and my role**.*
* This choice can still be changed by the researchers if it is likely to cause you any harm.

If I chose options a. or b., I understand that **no information that identifies me will be made publicly available**.

SensJus

8. *This question is optional, leave it blank if you do not consent. Otherwise encircle the option that applies to you.*
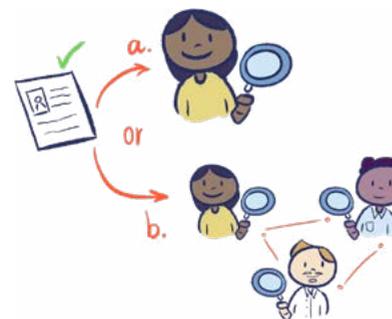
I give my consent for the data collected from my participation in this study to be used for **future research** by:

a. the same researchers

b. the same researchers **and** other researchers.

Any such future research will be aligned with the aims and values of this research.

Realities outside research, such as non-governmental organisations (NGOs), may want to use the collected data. This could be for purposes that you have not consented to here. If so, you will be notified and be given the chance to give or deny your consent for this.

_____ _____ _____
Name of participant   Date   Signature

_____ _____ _____
Name of researcher   Date   Signature

You will be given a copy of this signed document (consent form) to keep.

Contact details

If you have any questions or concerns regarding your participation in this research, please contact Anna Berti Suman at Anna.BERTI-SUMAN@ec.europa.eu.
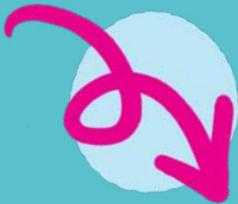
A Colourful Toolbox

Health Citizen Science under the GDPR

a collection of visual and written notes from the workshop "Health-Citizen Science Dilemmas Under the GDPR" held on the 12th and 13th October 2021, on the grounds of the Brocher Foundation and online.
For scientific inquiries, contact:
Anna.BERTI-SUMAN@ec.europa.eu
For artistic inquiries, contact:
aelisir.illustration@gmail.com
Fonts: Ultra, Franklin Gothic