

“Health-Citizen Science dilemmas under the GDPR”
Preliminary program

Brocher Foundation Symposium – Geneva (CH)
12-13 October 2021



SensJus



October 11

Get-to-know dinner at the Brocher Foundation

October 12 – DAY ONE

- Morning session (9:00-12:00):

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 [Carsten Lyng Obel]
- Public health interactions with citizen science [Sabine Wildevuur]

Coffee break

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]

--Lunch break and reflexive walk across the domain of the Brocher Foundation--

- Afternoon session (13:30-17:30)

Tensions and dilemmas between data protection and open science

- Experiences from the US context and the American Citizen Science Association [Lea Shanley]
- From the 2018 study to present experiences from the SensJus project [Anna Berti Suman]
- The Holland Health Data Cooperative take on the GDPR [Gaston Remmers]

The role of law and regulations in harmonizing openness and data protection

- Resisting a neoliberalism trend in health and medicine [Motahareh Bollon]
- When the patient/citizen scientist becomes consumer [reflections from Teresa Scassa]
- The JRC study on data management in citizen science projects [Chrysi Tsinaraki]

Coffee break

Health citizen science from the lens of sociology

- When health citizen science meets environmental crises [Bruna De Marchi]
- From self-tracking to self-expertise [Nils Heyen]
- Focus on Covid reality: health citizen science, pandemic and vaccinations [Katharina Paul]

Reactions from the participants

Live drawings explained by artist [Alice Toietta]

Dinner at the Brocher Foundation

- 21:00: Presentation of the book 'Legal, social and ethical perspectives on health & technology' edited by [Motahareh Bollon] and [Anna Berti Suman]

October 13 – DAY TWO

- Morning session (8:30-12:00):

Focusing on (environmental) health citizen science cases, benefits, implications & challenges:

- The experience of Pusaqua 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]

Coffee break

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]

--Lunch break and reflexive walk across the domain of the Brocher Foundation--

- Afternoon session (13:00-15:00)

Legal focus: 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]

Coffee break

Reactions from the participants and reflections towards a future research agenda and advice for practitioners dealing with health-related Citizen Science

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

Departures

NB: **green** → in person; **yellow** → virtual participant