

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

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



October 11

*Get-to-know dinner at the Brocher Foundation*

**From 18:30 to 20:30 at Villa Brocher**

October 12 – DAY ONE

- Morning session (9:00-12:15):

**(9-9:30) 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

**(9:30-10) Roundtable on ‘sensing’ the expectations for the symposium among the participants**

**(10-11) 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]

*Coffee break*

**(11:15-12) 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]

**(12-12:15) 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 (13:30-17:00)

**(13:30-14:30) 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]

**(14:30-15:30) 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]

*Coffee break*

**(15:45-16:45) 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]
- COVID-19 vaccination governance: valuing knowledge production and expertise in contemporary democracies [Katharina Paul]

**(16:45-17:00) Reactions from the participants**

Live drawings explained by artist [Alice Toietta]

*Dinner from 18:30 to 20:30 at Villa Brocher*

- 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):

**(8:30-10:15) 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*

**(10:30-12:00) 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)

**(13-13:30) Tensions between GDPR concerns and access to information held by authorities in matters concerning public and environmental health [Veronica Dini; Anna Berti Suman]**

**(13:30-14:00) A network for health citizen science: the ECSA Working Group experience, the survey [Gaston Remmers; Sabine Wildevuur]**

*Coffee break*

**(14:15-15:00) Reflections towards a future research agenda and advice for practitioners**

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

*Departures*

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