

“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

October 12

- 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]
- ➔ Public health interactions with citizen science [Sabine Wildevuur; Lea Den Broeder]

Coffee break

Ethical dimensions of (health) research with citizen scientists

- ➔ A needed focus on diversity in assessing citizen science [Dana Mahr]
- ➔ The perspective of the bioethicist and the experience of Brazil [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

- ➔ From the 2018 study to present experiences from the SensJus project [Anna Berti Suman]
- ➔ Experiences from the US context and the American Citizen Science Association [Lea Shanley]

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

- ➔ When the patient/citizen scientist becomes consumer [Teresa Scassa]
- ➔ Resisting a neoliberalism trend in health and medicine [Motahareh Bollon]

Coffee break

Health citizen science from the lens of sociology

- ➔ When health citizen science meets environmental crises [Ine Van Hoyweghen]
- ➔ From self-tracking to self-expertise [Nils Heyen]
- ➔ Focus on the Covid reality: health citizen science, the pandemic and vaccinations [Katharina T. Paul]

Reactions from the participants

Live drawings explained by artist [Alice Toietta]

Dinner at the Brocher Foundation

October 13

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

Focusing on health citizen science cases, their benefits, implications and challenges:

- ➔ The TOPFIT Citizen Lab in Twente [Karine Van Leersum]
- ➔ The Patient Science project [Nils Heyen]
- ➔ Experiences from the CitiesHealth project [Annibale Biggieri]

Coffee break

Follows on ongoing projects and pilots:

- ➔ The CSI COP project on GDPR and apps [Huma Shah; Robin Pierce]
- ➔ Participatory epidemiology: Aria di Ricerca [Bruna De Marchi]
- ➔ The perspective of Ideas for Change [Valeria Righi]

--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; Lea Den Broeder]

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