

BBMRI-ERIC'S STAKEHOLDER FORUM

PATIENT PILLAR

Workshop

"Building a Trusted Research Environment"

18 October 2021, h. 9.00-12.00 CEST (Vienna, Rome time)

<https://cesnet.zoom.us/meeting/register/tJMvc--hrzouG9Q6T6AXdA3ibiRW-G5i6-Ua>



“Why would I give my health data to a bunch of mad scientists, computer hackers and identity thieves?”

Fear, skepticism and lack of information surrounding the sharing of health data is widespread.

That’s why BBMRI-ERIC is organizing a workshop on “**Building a Trusted Research Environment**”. The event will open the discussion on creating Trusted Research Environments (TREs) for data-sharing in health research, and it aims to outline the current landscape and contexts, provide new focus for National Nodes and patients’ organizations and show examples of good practice in developing and using Trusted Research Environments.

The event was evolved from discussion between Austrian National Node, Stakeholder Forum Patient Pillar and BBMRI-ERIC’s HQ. It will be of interest to all National Nodes, and it also addresses one of the priorities of BBMRI-ERIC’s Stakeholder Forum Patient Pillar.

AGENDA:

9.00-9.15	Welcome <u>Jens Habermann</u> , BBMRI-ERIC's Director General <u>Iliaria Colussi</u> , Secretariat of BBMRI-ERIC's Stakeholder Forum <u>Kurt Zatloukal</u> , National Node Director of BBMRI Austria <u>Stefanie Houwaart</u> , BRCA network - help for people affected by hereditary cancers and German Cancer Aid
9.15 - 9.40	Methodological issues about Trusted Research Environments <u>Ulrike Felt</u> , University of Vienna (Austria)
9.40 - 10.20	A bio-ethical and legal dialogue <u>Dorota Krekora-Zajac</u> , University of Warsaw (Poland) <u>Giovanni Boniolo</u> , University of Ferrara (Italy)
10.20 – 10.30	Q&A
10.30 – 10.40	Break
10.40 – 11.00	Contribution and experience <u>Angelo Loris Brunetta</u> , Thalassaemia International Federation and Italian Foundation 'L. Giambrone' for the cure of Thalassaemia and Sickle-cell disease (FITHAD)
11.00 – 11.40	Psychological and bio-informatics inputs <u>Kalypso Iordanou</u> , University of Central Lancashire (United Kingdom and Cyprus) <u>Esther van Enckevort</u> , University Medical Center, Groningen (the Netherlands)
11.40 – 12.00	Q&A and concluding remarks

REGISTRATION:

The meeting will take place online on ZOOM.

Please register by 8 October 2021 to receive the meeting details:

<https://cesnet.zoom.us/meeting/register/tJMvc--hrzouG9Q6T6AXdA3ibiRW-G5i6-Ua>

LEARN MORE:

To find out more about the BBMRI-ERIC Stakeholder Forum Patient Pillar, visit

<https://www.bbmri-eric.eu/stakeholder-forum/>