

Conference

Public and Patient Involvement in Health Data Governance

15th July 2022 - Institute of Public Health, University of Porto (ISPUP)

Program

09h45: Opening session: Cláudia de Freitas, ISPUP | ITR

10h00: Session I: Social and ethical issues in health data sharing

Chair: Ana Azevedo, ISPUP | ITR

Public and patient participation in decisions about health data sharing, access, use and reuse

Ngozi Nwebonyi, ISPUP | ITR 

Public views on genomic data sharing: An Australian perspective

Danya Vears, Murdoch Children's Research Institute | Melbourne Law School

11h15 - 11h30: Coffee/tea break

11h30: Session II: Public involvement in data governance and stewardship

Chair: Mauro Serapioni, CES - University of Coimbra*

Public and patient perspectives about involvement in health data governance

Cláudia de Freitas, ISPUP | ITR

Participatory methods for studying and stewarding Data: Lessons from the Ada Lovelace Institute Health Programme Research

Kira Allmann, Ada Lovelace Institute

13h - 14h00: Lunch

14h00: Session III: Stakeholder-led innovation and future research in rare diseases

Chair: Maria João Baptista, CHUSJ | Reference Centre for Congenital Heart Diseases

Delivering patient-centred projects in an academic institution: From basic research to clinical research and innovation

Begoña Nafria, Hospital Sant Joan de Déu Barcelona 

Human-centred solutions in health care driven by and for citizens

Vanessa dos Reis Ferreira, Nova University of Lisbon | CDG & Allies - PPAIN

Title - TBA

Paulo Gonçalves, RD-Portugal 

15h30: Closing session: Henrique Barros, ISPUP | ITR; Cláudia de Freitas, ISPUP | ITR

16h00: Coffee/tea

*To be confirmed

Conference held in the scope of the project 'Public and patient involvement in health data governance: a people-centred approach to data protection in genetic diseases' (PTDC/SOC-SOC/32194/2017); <https://datagov-involve.wixsite.com/datagov>