

We have shown how **rare disease research data** can be made Findable, Accessible, Interoperable and Reusable (**FAIR**) whilst ensuring **good data protection practices** through semi-automated support for researchers.

Rare diseases: making environmental health studies' data as open as possible

Albert Navarro-Gallinad¹, Maria Christofidou², Solange Gonzalez Chiappe³, Fabrizio Orlandi¹, Nathan Lea², Dipak Kalra² and Declan O'Sullivan¹

Data protection problem!

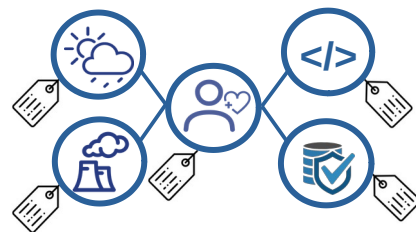


Location and time from environmental data

Context from a person's rare disease

Data protection risk without effective anonymization

Our solution: an approach that yields data that can be published as open as possible!



Region-season alike example data as a data table and a graph

Transparent metadata record as a graph

MCAA Annual Conference 2022



Horizon 2020
European Union Funding
for Research & Innovation



¹ ADAPT Centre for Digital Content, Trinity College Dublin, Dublin, Ireland

² The European Institute for Innovation Through Health Data (i-HD), Ghent, Belgium

³ Department of Rheumatology, Kantonsspital St.Gallen, St. Gallen, Switzerland