

Bridging the gap between researchers and the Health & Life Sciences research infrastructures

Showcasing EATRIS, BBMRI, ECRIN and ELIXIR tools & resources



June 13 & June 14, 2023

[Paushuize](#), Kromme Nieuwegracht 49, Utrecht & online via Zoom

Organization:

Lygature: Jan-Willem Boiten (EATRIS-NL), Robin Verjans (BBMRI-NL), Ilse Custers, Irina Stoica

Health-RI: Celia van Gelder (ELIXIR-NL), Jacqueline de Beer

INTRODUCTION

The joint life-sciences research infrastructures (RIs, e.g., EATRIS, BBMRI and ELIXIR) develop and provide services for specific research communities helping to solve bottlenecks and push forward the frontiers of scientific disciplines. In practice we see that the user community is often unaware or insufficiently aware of the services available to them. On the other hand, RIs developing the tools and resources need to stay in touch with a broad range of potential users to get a clear picture of their actual needs. In the Netherlands, Health-RI aims to be a connector for the national research communities and institutes to get/be optimally aligned with the new developments in the European Research Infrastructures. This workshop is dedicated to showcase several resources developed in Research Infrastructures: context, get feedback on those resources from foreseen users and hence help bridge the (perceived) gap between research infrastructures and the broader user community.

TARGET AUDIENCE

The workshop is targeted at (coordinators of) data support professionals who want to get acquainted with tools and resources of the Life Science Research Infrastructures that are available for them and the researchers they support. In addition, they will have the opportunity to provide feedback about the usability of these tools and resources.

PROGRAMME DAY 1 - JUNE 13 2023, 12:00-17:00 CEST

Chair: Celia van Gelder

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| 12:00 - 13:00 | Arrival and lunch for f2f participants - 12:30 Zoom room open for virtual attendants |
| 13:00 - 13:10 | Welcome on behalf of Health-RI - Jan-Willem Boiten, Health-RI, Lygature (slides) |
| 13:10 - 13:35 | Reflections about the role of RIs in accelerating research
Niklas Blomberg - director ELIXIR and coordinator EOSC-Life (remote, slides) |

- 13:35 - 14:15 **Theme: Data stewardship Skills**
- FAIR Data stewardship training & capacity building - *Celia van Gelder, Health-RI/ELIXIR-NL* ([slides](#))
- Data stewardship Community building - *Mijke Jetten, Health-RI/ELIXIR-NL* ([slides](#))
- 14:15 - 15:05 **Theme: FAIR data management & implementation (part 1)**
- Data management planning in DSW - stepping stone for implementation
Espen Åberg, ELIXIR-Norway ([slides](#))
- RDMkit – The Research Data Management toolkit for Life Sciences -
Munazah Andrabi, University of Manchester ([slides](#))
- 15:05 - 15:30 BREAK
- 15:30 - 17:00 **Theme: FAIR data management & implementation (part 2)**
- FAIRsharing - A curated, informative, and educational resource on data and metadata standards, inter-related to databases and data policies
Allyson Lister, FAIRsharing Content & Community Lead, University of Oxford (remote) ([slides](#))
- The FAIR Cookbook: a resource for and by FAIR doers in the life sciences -
Tooba Abbassi-Daloui, Maastricht University ([slides](#))
- The MDR: A Metadata Repository for Clinical Research - *Steve Canham, ECRIN* ([slides](#))
- 17:00 DRINKS

PROGRAMME DAY 2 - JUNE 14 2023, 9:30-13.00 CEST

Chair: Jan-Willem Boiten

- 9:00 - 9:30 Welcome; coffee and tea - 9:15 Zoom room open for virtual attendants
- 9:30 - 10:10 **Keynote lecture: FAIR patient registries and omics data for modeling disease trajectories**
Peter-Bram 't Hoen, Radboudumc ([slides](#))

10:10 - 11:10 **Theme: Sensitive data sharing**

Toolbox for sensitive data sharing - *Christian Ohmann, ECRIN* ([slides](#))

The Netherlands ELSI service desk - *Miriam Beusink, Health-RI* ([slides](#))

BBMRI ELSI Service - *Michaela Mayrhofer, BBMRI-ERIC* ([slides](#))

11:10 - 11:30 BREAK

11:30 - 12:50 **Theme: Sharing high-quality biosamples and patient engagement**

BBMRI-ERIC Quality Management Services and involvement in EU projects
Maike Tauchert, BBMRI-ERIC & EPND project ([slides](#))

Dutch biobanking standard: Towards harmonized & evidence-based protocols
Hilde Brouwers, Health-RI, Erasmus MC ([slides](#))

Creating large international data federations using MOLGENIS
Morris Swertz, UMCG/BBMRI/ELIXIR ([slides](#))

Patient engagement in Translational Research – why, how, and when
Florence Bietrix, EATRIS-ERIC ([slides](#))

13:00 Closure

Packed lunch