

## **EuRRECa/EuRR-Bone Data Access Committee Remit**

The overall aim of the DAC is to promote the wider use of the data that are being collected in the EuRRECa/EuRR-Bone core registry and e-REC through a transparent and simple approach ensuring the long-term sustainability of the registry platform.

The DAC should advise on the maintenance of the highest levels of custodianship of the data. Whilst it should have a good knowledge of ethics and data protection, it should not act as another 'research ethics committee' which is a responsibility that rests at the level of the data controllers.

The DAC will review:-

- all new applications
- existing projects
- end of project reports
- and any other outputs

Specific tasks of the DAC include:-

- check that the proposed work complies with the terms and conditions of the ethics approval provided to the EuRRECa core registry project, see <https://eurreca.net/ethics-approval-coreregistry/>
- look for evidence that the third party who is requesting the data is appropriately qualified for use of the data;
- advise on improving the scientific content and feasibility of the projects and any overlaps with ongoing projects;
- advise on the dissemination and publication plans;
- ensure that the effort of all those involved is appropriately acknowledged;
- provide feedback to the requestor
- review and advise on the governance processes within the DAC

All members of the DAC shall

- serve a 4-year term renewable for another 1 yr
- communicate to the EuRRECa/EuRR-Bone Project Management Group through the Chair of the DAC who will represent the DAC in the Steering Committee
- complete a conflict of interest form
- declare any specific conflicts when reviewing an application
- treat all data requests confidentially
- Aim to respond to all data requests promptly
- Be familiar with the Data Access Policy and ethics approval of the EuRRECa/EuRR-Bone Core Registries
- <https://eurreca.net/data-access-process/>
- <https://eurreca.net/ethics-approval-erec/>
- <https://eurreca.net/ethics-approval-coreregistry/>

Date of original creation of the remit: 23/06/21

Date of revision:

Date for next revision: June 2023

For further reading, Cheah, P.Y., Piasecki, J. Data Access Committees. *BMC Med Ethics* **21**, 12 (2020). <https://doi.org/10.1186/s12910-020-0453-z>

The Data Access Committee includes:-

<b>Role</b>	<b>Name</b>	<b>Join</b>	<b>Demit</b>
Chair	Olaf Dekkers	2022	2026
EuRECa Lead	Faisal Ahmed	2019	NA
EuRR-Bone Project Lead	Natasha Appelman-Dijkstra	2020	NA
Chair of Steering Committee	Agnès Linglart	2022	2026
ESPE	Olaf Hiort	2022	2026
Endo-ERN	Pietro Maffei	2022	2026
ESE	Kristi Alexandraki	2022	2026
ECTS	Carola Zillikens	2021	2025
ERN BOND ePAG	Tenna Toft	2021	2025
Endo-ERN ePAG	Arlene Smyth	2019	2023
Bone Expert	Gabriele Haeusler	2021	2025
Bone Expert	Roland Chapurlat	2020	2024
EuRECa/EuRR-Bone Fellow	Ana Priego	2020	2024
Fellow	Mariya Cherenko (Observer)		
Project Manager	Tess de Rooij	2022	NA
Project Manager	Jillian Bryce	2019	2023

Panel updated: 18/08/22