



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 <u>Ethics</u>
 <u>Approval</u> provided to the EuRRECa/EuRR-Bone core registry project.
- 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 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 <u>Data Access Policy</u>, <u>Data Access Process</u>, and <u>Ethics Approval</u> of the EuRRECa/EuRR-Bone Core Registries

Date of original creation of the remit: 23/06/2021

Date of revision: 30/10/2023

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:

Role	Name	Join	Demit
Chair	Olaf Dekkers	2022	2026
EuRRECa Project Lead	Faisal Ahmed	2019	NA
EuRR-Bone Project Lead	Natasha Appelman-Dijkstra	2020	NA
Chair of Steering	Agnès Linglart	2022	2026
Committee			
ESPE	Olaf Hiort	2022	2026
Endo-ERN	Pietro Maffei	2022	2026
ESE	Kristi Alexandraki	2022	2026
ECTS	Carola Zillikens	2021	2025
ISCBH	Ciara McDonnell	2024	2028
ISCBH	Adalbert Raimann	2024	2028
ERN BOND ePAG	Tenna Toft	2021	2025
Endo-ERN ePAG	Arlene Smyth	2019	2023 +1
Bone Expert	Gabriele Hartmann	2021	2025
Bone Expert	Roland Chapurlat	2020	2024
Project Manager	Tess de Rooij	2022	NA

Panel updated: 05/08/2024