

The Office for Rare Conditions Registries (ORC Registries)

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Institution

Educational Institution

Non EU Institution/Body/Agency

Non-Pharmaceutical company

Institution identification

Institution ID

1000000905

Institution countries

 United Kingdom

Type of institution

Educational Institution

Non EU Institution/Body/Agency

Non-Pharmaceutical company

Institution role

Data holder

Data provider

Researcher

Institution website

<https://www.gla.ac.uk/schools/medicine/research/childhealth/theofficeforrarecon...>

ENCePP partner

Yes

Institution description

The Office for Rare Conditions Registries, is a University of Glasgow project, based at Child Health, which focusses on the developemnt and operation of registries for rare conditions. The project team has been involved in rare disease registries for two decades.

Amongst its portfolio are :

- SDMregistries for people with conditions affecting sex development and maturation.
- GloBE-Reg, a registry which supports post authorisation studies for new therapies for bone and endocrine conditions.

Institution details

Experience with collecting data directly from individual patients or respondents:

Yes

Interest in carrying out research that is funded by pharmaceutical companies:

Yes

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