

# EuRRECa Survey for Affiliate Registries

**Respondent:**

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**Response on:**

11.05.2023, 10:45 - 11.05.2023, 10:50

## 1. **Background**

This tool has been developed for registries seeking affiliate status to the European Registries for Rare Endocrine Conditions (EuRRECa). A small number of quality criteria regarded as essential for the quality of a disease registry have been derived from the article "Recommendations for Improving the Quality of Rare Disease Registries" (available from <https://pubmed.ncbi.nlm.nih.gov/30081484/>). The acceptability of these quality criteria in the self-evaluation of rare disease registries have been reported amongst the rare disease community (available from <https://www.mdpi.com/1660-4601/18/22/11968>). It is not necessary to fulfill all the criteria for obtaining affiliate status.

## **Governance**

The EuRRECa project was launched in 2018 ([eurreca.net](http://eurreca.net)) and this survey was developed by Work Package 3 (Quality Assurance & Evaluation). The survey questionnaire utilises Webropol, a secure on-line platform that is endorsed and supported by NHS Greater Glasgow & Clyde and NHS Scotland. All information provided will be kept in compliance with the UK Data Protection Act (2018) and General Data Protection Regulation (GDPR 2016/679).

## **Further information**

Please contact Jillian Bryce, EuRRECa project manager ([info@eurreca.net](mailto:info@eurreca.net))

**I confirm that I have read the above information and I am happy to proceed to the application form**

Yes

## 2. Contact details for respondent

Name	Jillian Bryce
Email	<a href="mailto:jillian.bryce@glasgow.ac.uk">jillian.bryce@glasgow.ac.uk</a>
Institution	University of Glasgow
Name of Registry	GloBE-Reg
Registry website	<a href="https://globe-reg.net/">https://globe-reg.net/</a>

## 3. Governance

	Yes	No
Does the registry have a named lead?	<input checked="" type="radio"/>	<input type="radio"/>
Named lead: <input type="text" value="Prof S. Faisal Ahmed"/>	<input checked="" type="radio"/>	<input type="radio"/>
Does the registry have a management team?	<input checked="" type="radio"/>	<input type="radio"/>
Are patients involved in the governance of the registry?	<input checked="" type="radio"/>	<input type="radio"/>
Does the registry have a long-term sustainability plan?	<input checked="" type="radio"/>	<input type="radio"/>
Does the registry have ethics approval?	<input checked="" type="radio"/>	<input type="radio"/>
Does the registry have publicly accessible consent forms and participant information sheets?	<input checked="" type="radio"/>	<input type="radio"/>
Weblink to documents: <input type="text" value="https://globe-reg.net/information-sheets/"/>	<input checked="" type="radio"/>	<input type="radio"/>
Does the registry have a document outlining its standard operating protocol?	<input checked="" type="radio"/>	<input type="radio"/>
Does the registry disseminate its activity through a report or a newsletter?	<input checked="" type="radio"/>	<input type="radio"/>
Weblink to report or newsletter: <input type="text" value="https://globe-reg.net/newsletters/"/>	<input checked="" type="radio"/>	<input type="radio"/>

#### 4. Data quality

	Yes	No
Do the core data elements in the registry have a clear definition and coded values?	<input checked="" type="radio"/>	<input type="radio"/>
Link to Data Elements Definition: <input type="text" value="https://globe-reg.net/data-elements/"/>	<input checked="" type="radio"/>	<input type="radio"/>
Does the registry specify who is responsible for entering the clinical data?	<input checked="" type="radio"/>	<input type="radio"/>
Does the registry have procedures for checking data quality?	<input checked="" type="radio"/>	<input type="radio"/>
Does the registry provide training to all users?	<input checked="" type="radio"/>	<input type="radio"/>

#### 5. IT infrastructure

	Yes	No
Does the registry have a web interface?	<input checked="" type="radio"/>	<input type="radio"/>
Does the web-interface allow uploading and downloading of data?	<input checked="" type="radio"/>	<input type="radio"/>
Does the registry have data breach procedures in place?	<input checked="" type="radio"/>	<input type="radio"/>
Does the registry have clear procedures for erasing personal data when requested?	<input checked="" type="radio"/>	<input type="radio"/>
Does the registry have clear procedures that only allow authorised users to have access to registry data?	<input checked="" type="radio"/>	<input type="radio"/>

6. Do you have any additional comments?

At the moment documents can be uploaded to a patient record but in the near future we will have a bulk upload function to import bulk downloaded data from other data sources