

Submitting Data to CI5-XIII

1. New IARC/CSU Data Collection Portal
2. Data and documentation requirements

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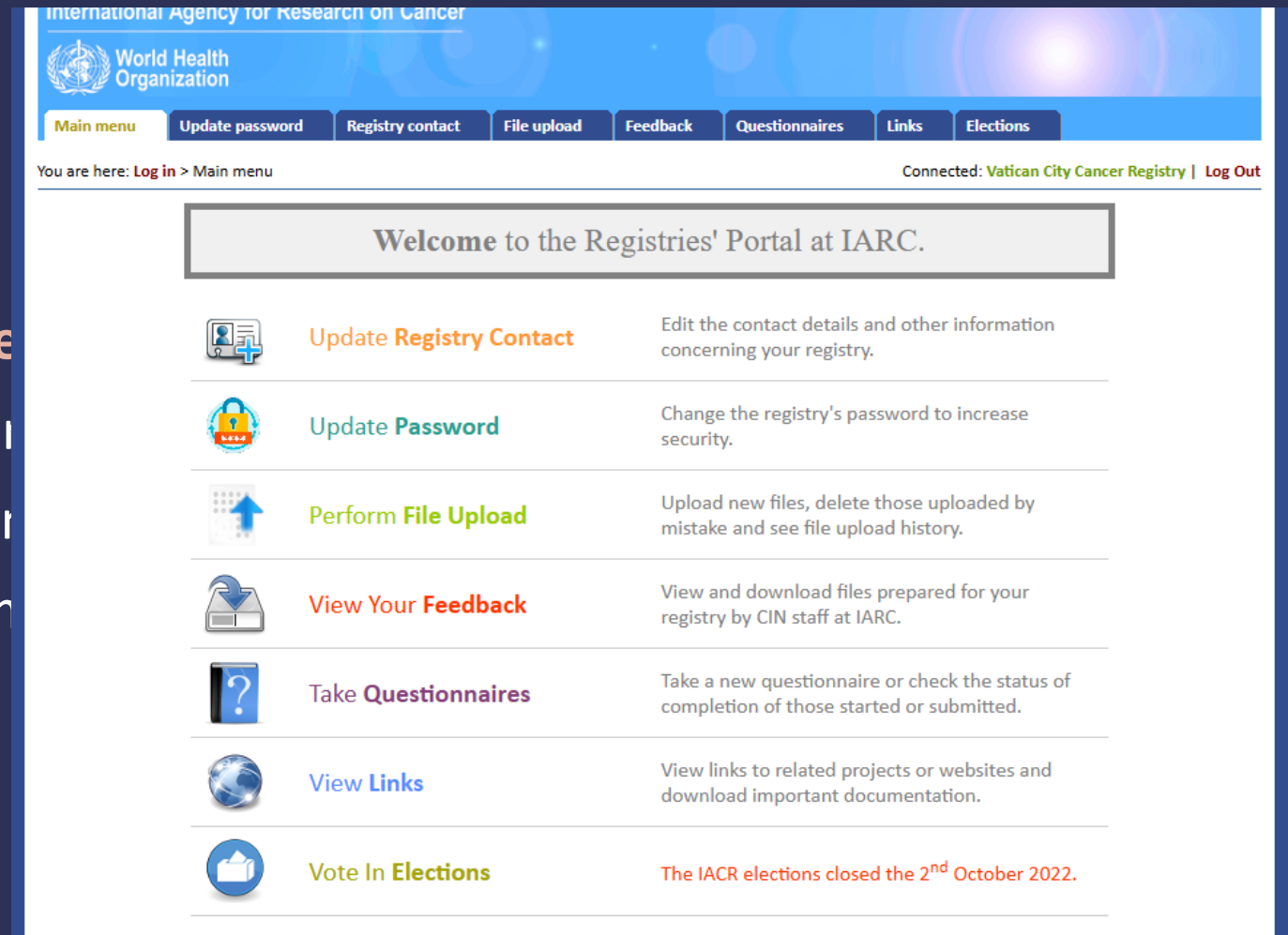
New IARC/CSU Data Collection Portal

IARC Registries Portal

~15 years of good and loyal service

Why transition to a new data collection portal?

- Support changing data collection requirements
- Align with current data management practices
- Easier to maintain, adapt, and improve

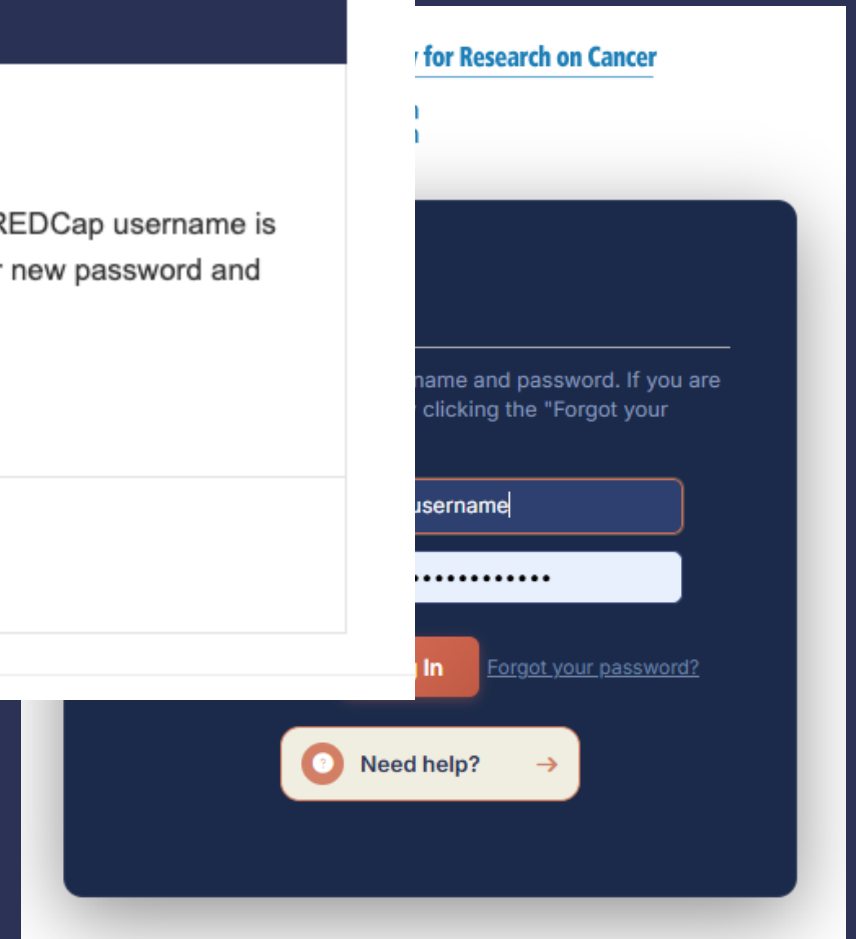
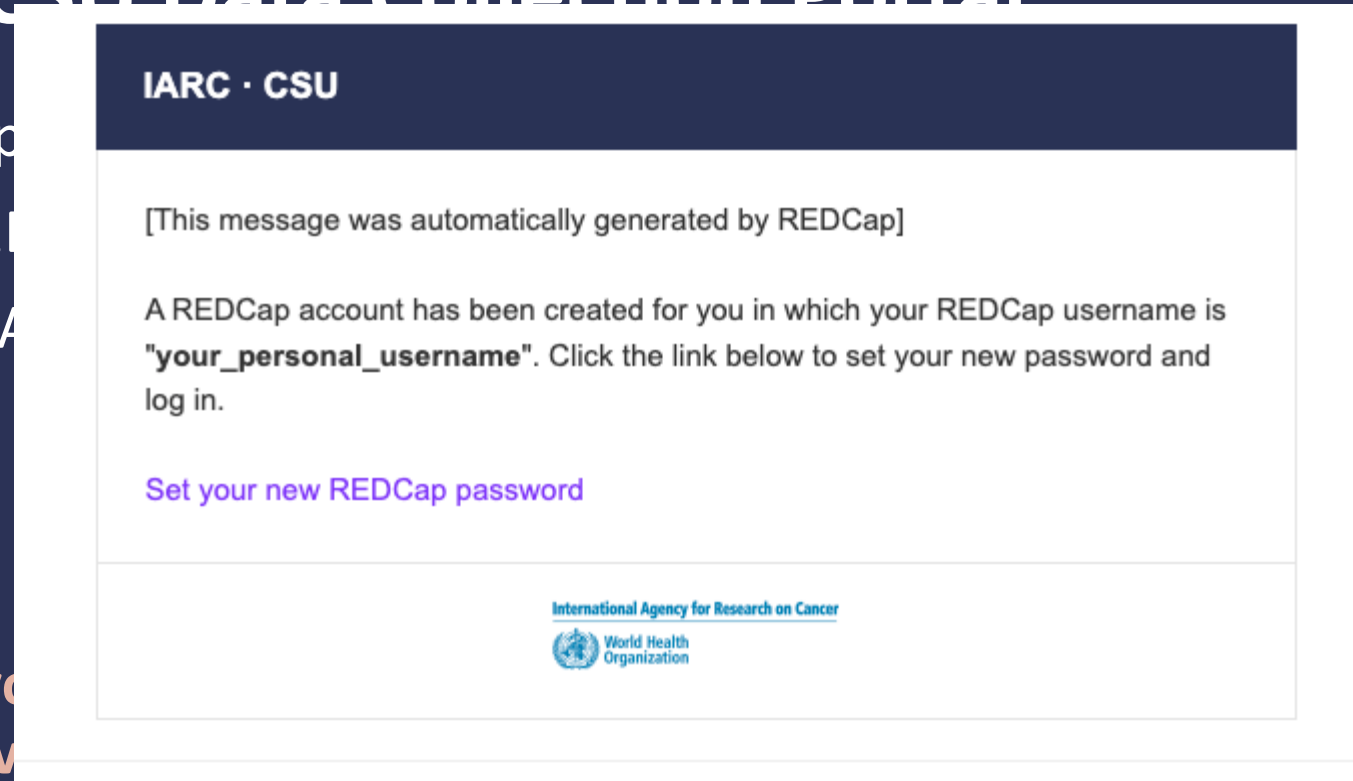


New IARC/CSU Data Collection Portal

- Launched 1 Sep
- Powered by REDCap
- Host multiple IARC

➤ Username and email

⚠ Please check your email if you received an invitation



New IARC/CSU Data Collection Portal

Never submitted data to CSU?

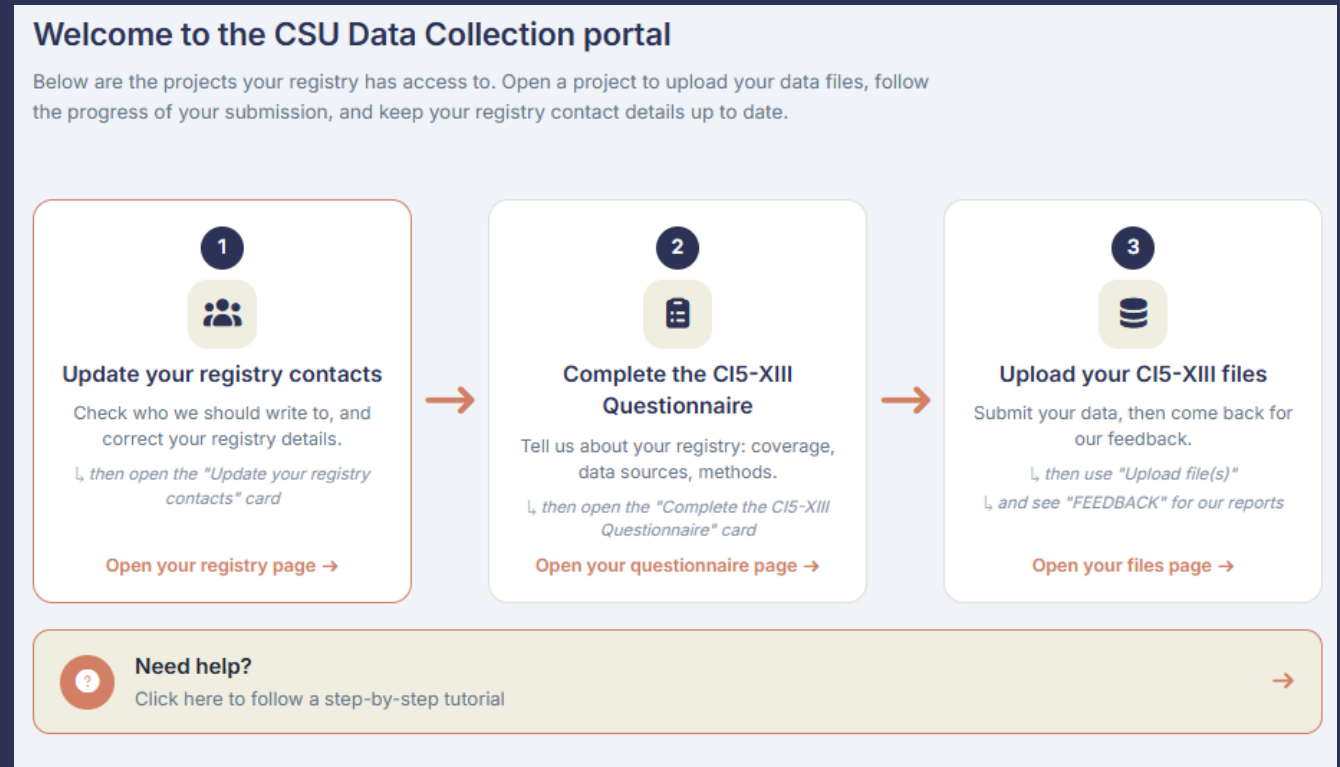
Contact us at ci5@iarc.who.int to register for access to the Data Collection Portal.

Please provide:

- Registry name
- Coverage area (national, regional, etc.)
- Name and email address of each user requiring access

New IARC/CSU Data Collection Portal

1. Update user profile
2. Update registry contacts
3. Complete CI5-XIII questionnaire
4. Submit data files
5. Receive & review feedback



<https://csu.datacollect.iarc.who.int/>

New IARC/CSU Data Collection Portal

? Lost? Check out the onboarding tutorial & FAQ

International Agency for Research on Cancer
World Health Organization

Log In

Please log in with your user name and password. If you are having trouble logging in, try clicking the "Forgot your password" link below.

Username:

Password:

[Log In](#) [Forgot your password?](#)

[Need help? →](#)

Welcome to the CSU Data Collection portal

Below are the projects your registry has access to. Open a project to upload your data files, follow the progress of your submission, and keep your registry contact details up to date.

1



Update your registry contacts

Check who we should write to, and correct your registry details.

↳ then open the "Update your registry contacts" card

[Open your registry page →](#)

2



Complete the CI5-XIII Questionnaire

Tell us about your registry: coverage, data sources, methods.

↳ then open the "Complete the CI5-XIII Questionnaire" card

[Open your questionnaire page →](#)

3



Upload your CI5-XIII files

Submit your data, then come back for our feedback.

↳ then use "Upload file(s)"

↳ and see "FEEDBACK" for our reports

[Open your files page →](#)

 **Need help?**

Click here to follow a step-by-step tutorial [→](#)

New IARC/CSU Data Collection Portal

Behind the new Data Collection Platform: A Team Effort

- Freddie Bray
- Murielle Colombet
- Anastasia Dolya
- Morten Ervik
- Maria (Chelle) Fernan
- Frederic Lam
- Jerome Vignat
- Aude Bardot



CI5-XIII: ci5@iarc.who.int

General queries/feedback: csu@iarc.who.int

This is a living platform. It is designed to evolve, and future enhancements will continue to be guided by user needs and future data collection activities.

Data and documentation requirements

CALL FOR DATA & DATA SPECIFICATION PROTOCOL

The **Call for Data** document provides detailed instructions on the content and process of the submission. It is accompanied by the official **invitation letter**. Both documents are available in English, French and Spanish.

Language	Call for Data & Data Specification Protocol	Invitation Letter
English	Call for Data	Invitation Letter
Français	Appel à données	Lettre d'invitation
Español	Convocatoria de datos	Carta de invitación

<https://the-iacr.net/en/ci5-2.0/about>

Data and documentation requirements

Incidence data

listing of **individual cancer cases**

Population data

number of residents for a combination of calendar year, sex and age
» from official censuses or intercensal/post-censal estimates

Mortality data

where available

number of deaths for a combination of calendar year, sex, age and cause of death
» preferably from official vital statistics offices

Population lifetable

where available

mortality probabilities for a combination of calendar year, sex and age
» preferably from official vital statistics offices

Coding file

if the coding rules differ from those requested in data protocol

Completion of the online questionnaire

provide details of the registry and the catchment population

Data and documentation requirements

Incidence data

listing of individual cancer cases

Patient Information	Tumour Information
Patient ID*	Tumour sequence #
Date of Birth*	Date of Incidence*
Sex*	ICD-O-3 Topography*
Age in years*	ICD-O-3 Morphology*
Ethnic group	ICD-O-3 Behaviour*
	ICD-O-3 version
	Basis of diagnosis*

Follow-up	Staging
Vital Status	TNM Stage
Date of Last Contact	TNM Edition

- 1 row = 1 unique patient-tumour combination
- Data quality checks prior to submission: IARCcrgTools

Any questions?

Thank you !



ci5@iarc.who.int
csu@iarc.who.int

International Agency
for Research on Cancer



World Health
Organization



GLOBAL INITIATIVE
FOR CANCER REGISTRY
DEVELOPMENT
INITIATIVE MONDIALE
POUR LE DEVELOPPEMENT
DES REGISTRES DU CANCER
INICIATIVA MUNDIAL
PARA EL DESARROLLO
DE REGISTROS DE CÁNCER

Useful links



ci5@iarc.who.int

csu@iarc.who.int

- IARC/CSU Data Collection Portal

<https://csu.datacollect.iarc.who.int/>

- CI5-XIII Data Protocol

<https://the-iacr.net/en/ci5-2.0/about>

- IARC Check Tool: IARCcrgTools

<https://the-iacr.net/en/standards/check-conversion-programs>

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