



REDCap Rare Cancer Database Clare Scott



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- On-line testing externally available end-November 2017
 - Complete generic database but modules are optional
 - The database will be available for free
 - One REDCap license required per country
 - Keep your data within your country until we develop international approaches for sharing
 - Developed with BioGrid Australia expertise
 - an instruction document will be available

Action Items

- Identify the optimal minimum dataset
- Consider consent form and process (unified consent if possible)



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Minimum dataset: to generate a stacked swimmers plot

- DOB
- Date of diagnosis
- Tumor/Histologic subtype
- Molecular abnormality/multiple
- Treatment + Date of first treatment
- Treatment + Date of each treatment
- Date of Death



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Consent for rare cancer studies: Data +/- access to stored tissue

Collection of medical information

You agree to allow your oncologist to provide the study doctors with information about your health and medical conditions. This information is collected as part of the study for 2 reasons:

- i) to ensure that it is appropriate for you to participate in this study,
- ii) to provide the study doctors with relevant medical information that will help them to interpret the gene changes found in your cancer.

The information which will be collected about you will include:

- Your medical history including details about your cancer, when/how you were diagnosed, the kinds of cancer treatments you have received, and your progress on these treatments. This may include information on your medical file including results of past scans and any molecular or special testing previously performed on your cancer, including genetic tests.
- Other health problems you may have
- We may ask you to give us health information about your relatives, relating to cancer or other genetic conditions which run in your family.
- Any complications that occur as a result of the blood tests which you will undergo as part of this study



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REDCap
Logged in as scottc | Log out
My Projects
Project Home or Project Setup
REDCap Messenger
Project status: Development

Data Collection
Record Status Dashboard
Add / Edit Records
Show data collection instruments

Applications
Data Exports, Reports, and Stats
Field Comment Log
RcDB Registration

Help & Information
Help & FAQ
Video Tutorials
Suggest a New Feature
Contact REDCap administrator

RcDB

Record Status Dashboard (all records)

Displayed below is a table listing all existing records/responses and their status for every data collection instrument (and if longitudinal, for every event). You may click any of the colored buttons in the table to open a new tab/window in your browser to view that record on that particular data collection instrument. Please note that if your form-level user privileges are restricted for certain data collection instruments, you will only be able to view those instruments, and if you belong to a Data Access Group, you will only be able to view records that belong to your group.

Legend for status icons:
● Incomplete ● Incomplete
● Unverified ● ● ● ● ●
● Complete ● Many sta

Dashboard displayed: [Default dashboard]
Displaying Data Access Group: -- ALL --
Displaying record: Page 1 of 1: "RCDB-MH-001" through "SFRC01" of 6 records | ALL (6) records per page

Displaying: Instrument status only | Lock status only | All status types

Patient UIN	Registration	Tumours	Tumour Blood & Urine Markers	Tumour Histological Markers	Tumour Genetics	Survival & Treatment Events	Samples - Tumour	Samples - Blood	Risk Factors	Comorbidities	IES-6
RCDB-MH-001	●	●+	●+	●	●	●	●	●+	●	●	●+
SFRC01036-CP-test	●	●+	●+	●+	●+	●+	●+	●	●	●	●
SFRC01040-CP-test	●	●+	●+	●+	●+	●+	●+	●	●	●	●+
SFRC01042-CP-test	●	●+	●+	●+	●+	●+	●+	●	●	●	●
SFRC01055-CP-test	●	●+	●+	●+	●+	●+	●+	●+	●	●	●+
SFRC01058-CP-test	●	●+	●+	●+	●+	●+	●+	●+	●	●	●+

Slide deck with data fields and sample consent available:

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