searchMECFS

Website User Guide
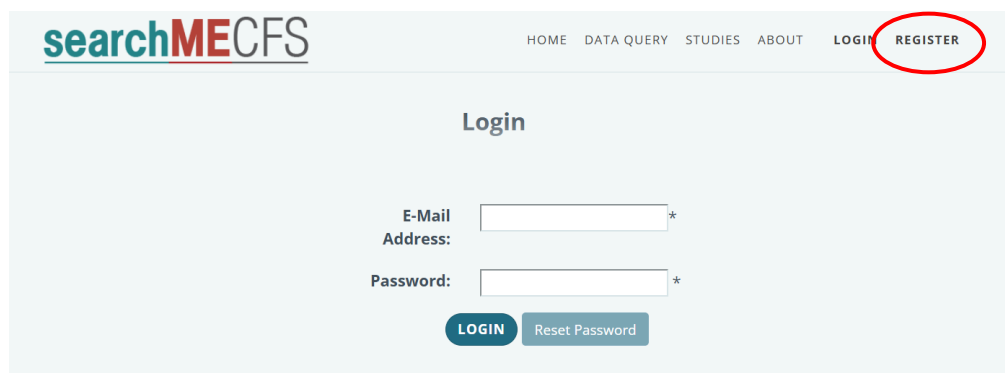
Version 2.0

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Contents

1. Introduction

searchMECFS is an interactive online data query tool for navigating biospecimens available for research purposes from studies of myalgic encephalomyelitis, also known as chronic fatigue syndrome (ME/CFS). The goal of searchMECFS is to facilitate biospecimen selection based on phenotypic and clinical attributes of study participants who contributed biospecimen samples, and to initiate the process of applying for access to selected biospecimens.

2. Creating a User Account

2.1 How to request access to searchMECFS

Users must register to access the data query functionality. Click Register in the upper right corner of the Login page.
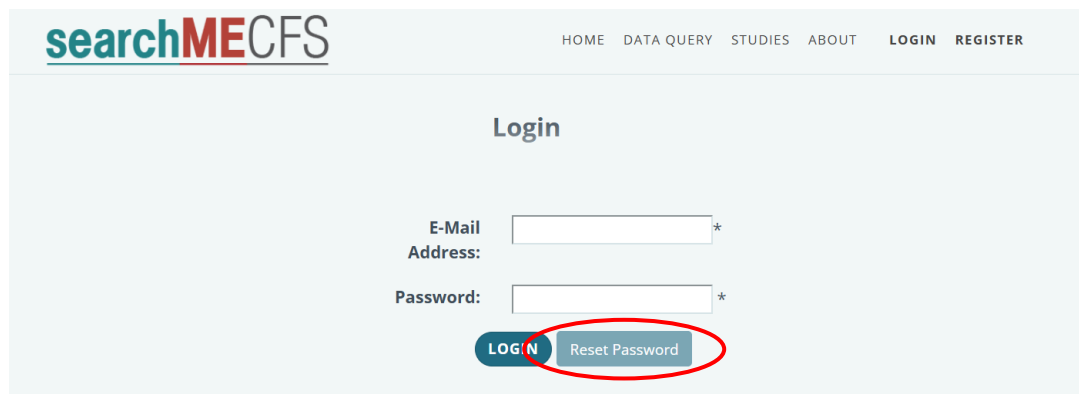

Provide the requested information, including your desired password and reason for requesting access to the system. Passwords must be at least 8 characters long and contain at least one letter and one number. Your registration request will be reviewed for approval. You will receive an email notification informing you whether your request was approved or denied.

2.2 Resetting your Password

From the Login page, select Reset Password.

You will be prompted to enter your email address. You will receive an email from searchMECFS@rti.org containing a temporary password. You will logon with your email address and the temporary password. Then the system will prompt you to create a new password.

3. searchMECFS Overview

searchMECFS displays six menu options at the top of the home page.

Home – link to return to the Home page.

Data Query – link to the biospecimen query page.

Studies – summaries of the Data Studies whose biospecimens are searchable. Includes study documents such as data dictionaries and codebooks.

About – informational pages about searchMECFS, including a system overview, instructions on submitting biospecimen requests, links to the user guide and demonstration videos, and FAQs.

Login – link to the system login page

Register – link to the new user account request page

The home page also displays a **Start a Query** link, which also links to the Data Query page.

Note that you must logon to access the Data Query page.

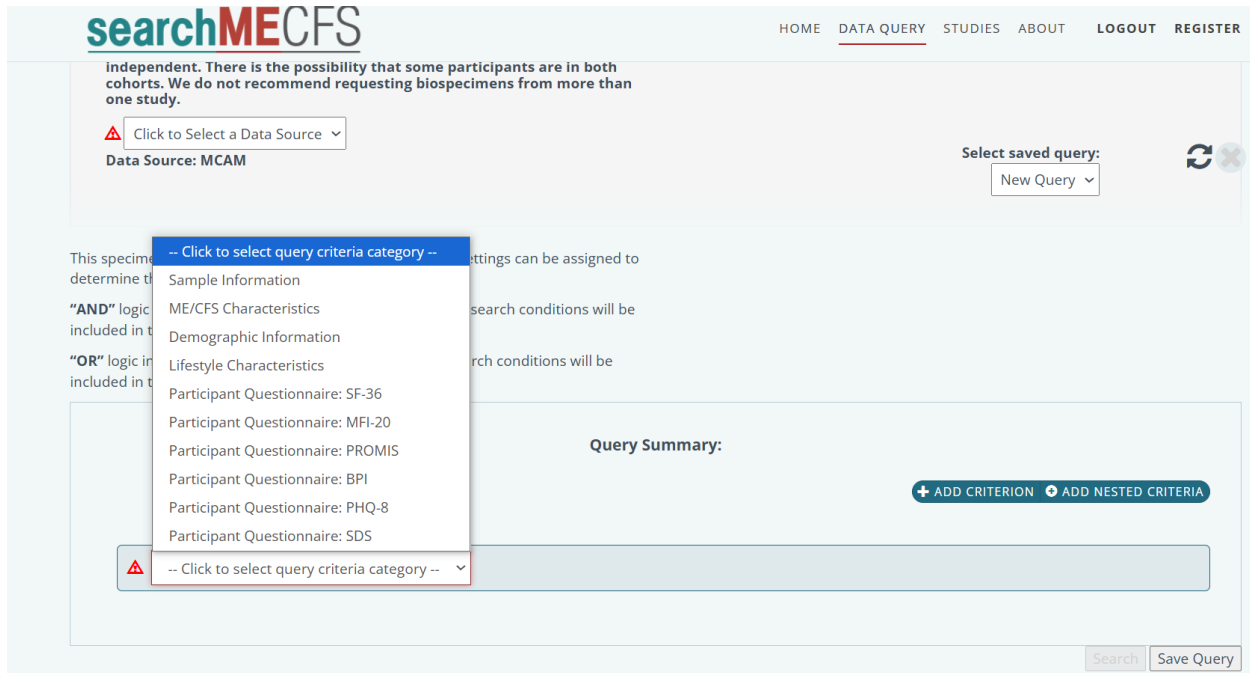## 4. Performing Data Queries

The searchMECFS query page facilitates building queries to search for biospecimens that meet selected criteria.

4.1 Query Tool Page Layout

The system initially displays options to select a Data Source and a Saved Query.
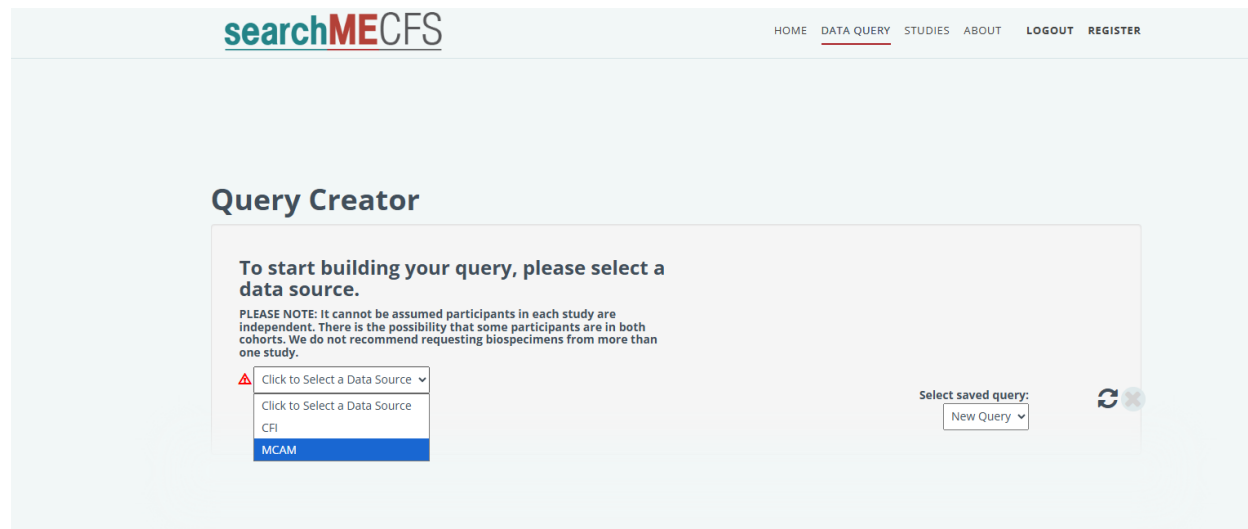
After a Data Source is selected, the system displays selectable Query Criteria categories.

Available query criteria are listed in the search bar dropdown list. A red icon left of the search bar indicates that the current search condition is incomplete or invalid. Upon opening the dropdown list and selecting a variable of interest, the search bar will display additional options to allow you to specify values or ranges based on the data type of the variable (e.g., Yes/No, Male/Female). When a valid search criterion has been created, the red search bar icon no longer displays, and the Query Summary statement will display above the search bar.

For example: To find **ME/CFS cases**, use ME/CFS Characteristics and select **ME/CFS Participant**
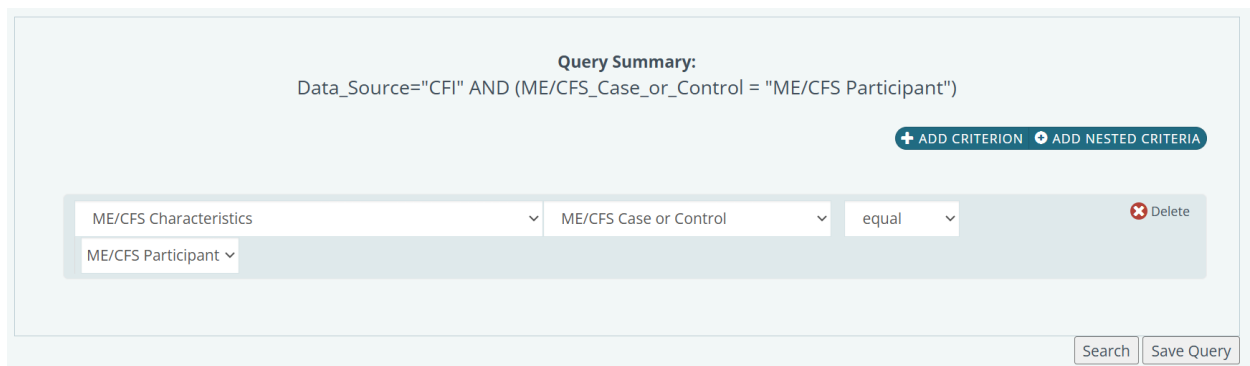
Click Search to execute the query. The system displays a deidentified list of available biospecimens that match your search criteria.

Query Results

Data_Source="CFI" AND (ME/CFS_Case_or_Control = "ME/CFS Participant")

Found **1804** specimens from **201** participants.

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PARTICIPANT ID	ME/CFS CHARACTERISTICS	SEX	AGE	SPECIMEN TYPE	SPECIMEN QUANTITY	AVAILABLE INVENTORY
2183	ME/CFS Participant	Male	23	DNA	3 ug	38
2183	ME/CFS Participant	Male	23	PBMC	1 ml	2
2183	ME/CFS Participant	Male	23	Plasma	100 ul	10
2183	ME/CFS Participant	Male	23	RNA	1 ug	8

4.2   Building Queries

You can add multiple search criteria to further enhance your search and limit the results. Queries consist of search criteria and nested criteria and are applied using ANY or ALL Boolean logic to discover data of interest.

4.2.1   Query Criteria

A query criterion is a single search condition that appears on a single line of the search bar. Multiple criteria may be executed together using the applied logic (see the AND/OR Logic section below). To add a new search criterion to your query, click Add Criterion in the upper right corner of the search bar. An additional empty criterion appears. Select a Query Category, variable, qualifier and value or value range to complete the new criterion. There is no limit to the number of criteria you can add to a query.

4.2.2   AND/OR Logic

"AND" logic indicates that only data records which meet all search conditions will be included in the results set. "OR" logic indicates data records which meet any of the search conditions will be included in the results set. Select the "AND" or "OR" option at the top left section of the search

bar to apply the appropriate logic to your query. If multiple criteria are added to the base query, they are executed together as a group using the selected "AND" or "OR" logic.

Note that "AND" logic is applied by default.
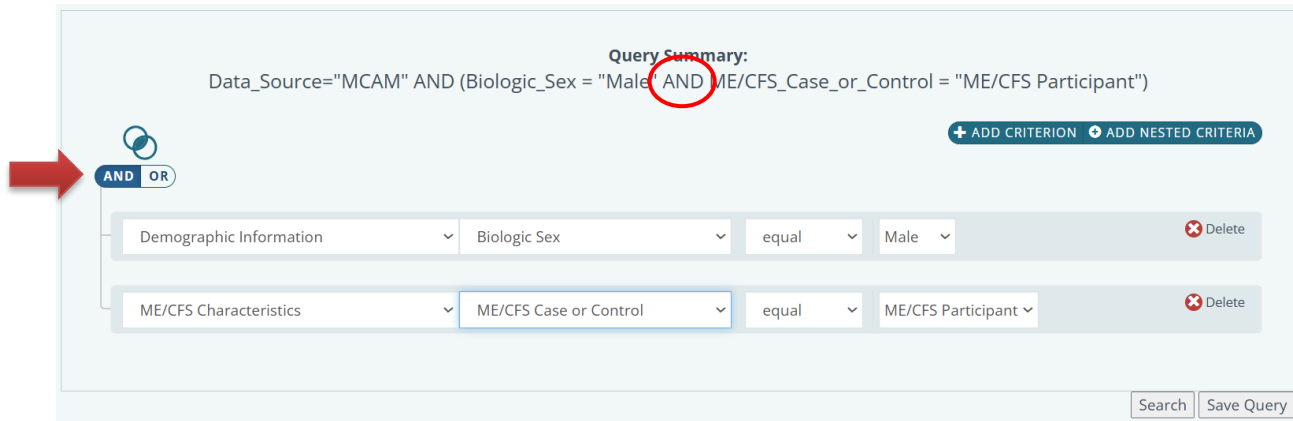
4.2.3 Nested Criteria

Nested Criteria are a collection of query criteria that are executed together. Nested criteria will be evaluated first, and the additional criteria will be applied to the nested criteria results to produce a final result set. Nested Criteria are used when you want to apply different "AND/OR" logic to different parts of your query. To add Nested Criteria to your query, click the Add Nested Criteria button in the upper right corner.

Rule of Thumb – if you are interested in searching on more than one value for a single categorical variable, or more than one range of values for a single numeric variable, use a nested query for that variable and its values. This is typically used when searching for more than one sample type.

For example: To find ME/CFS Participants that are Male (MECFS Participants AND Male) with available DNA specimens or RNA specimens (DNA OR RNA), use a Nested Query.
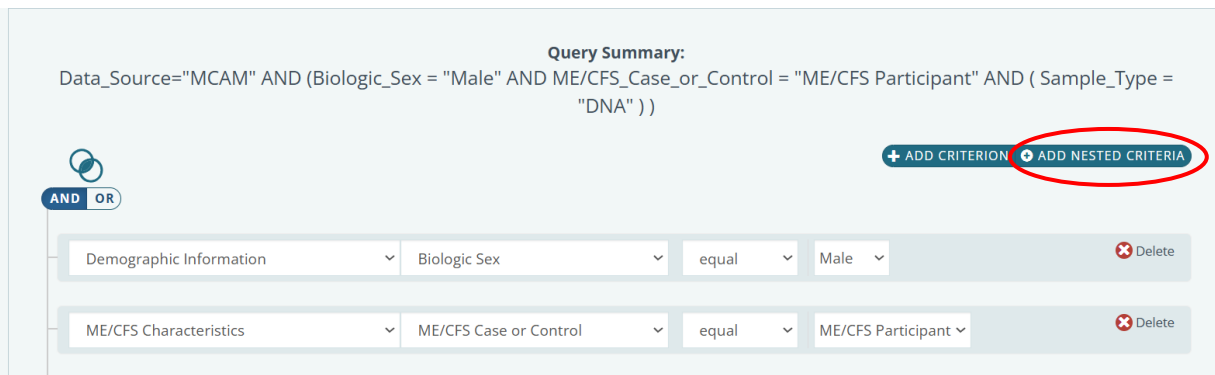
Nested Criteria will appear slightly indented in the search bar to identify them as nested. To select additional Nested Criteria, ensure you click the Add Criterion button within the nested group. Note that Nested Criteria also have an AND/OR selector. Make sure you apply the appropriate logic to each nested group.

4.2.4 Editing Queries

Query details can be edited at any time. You can remove existing rules or groups by clicking the red Delete icon to the right of the corresponding criterion.

4.2.5 Running Queries

When your query details have been entered, click Search to execute the query. The system will display the study participants and their biospecimens which meet your search criteria.

Each row in the results set represents a biospecimen from a specific deidentified study participant. The count at the top of the results set indicates the number of unique biospecimens in the results set and the number of study participants from whom they were collected.

4.2.6   Saving Queries

Any valid query (i.e., any query with no red search icons) can be saved. To save a query, click the Save Query button. The system will display a pop-up and prompt you to enter a name for your query. The Save Query button on the pop-up is disabled until a valid name is entered for the query.

Note that you **must** click Save Query to save the query – hitting the Enter or Return key will not save the query.
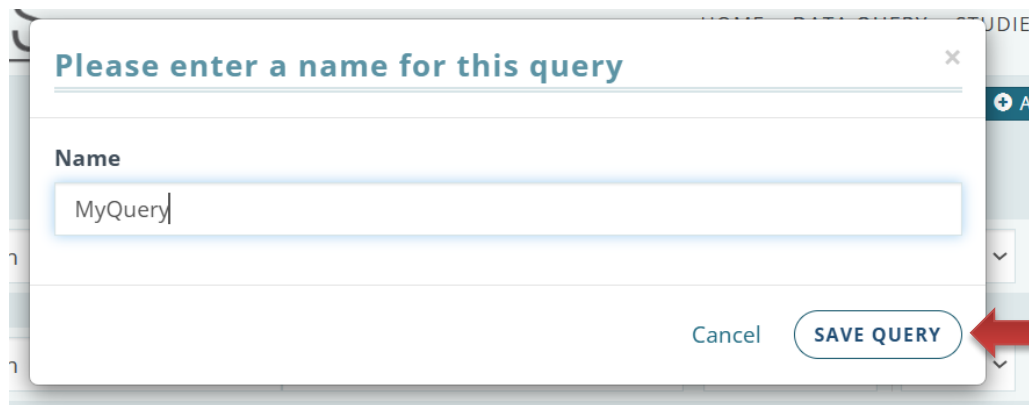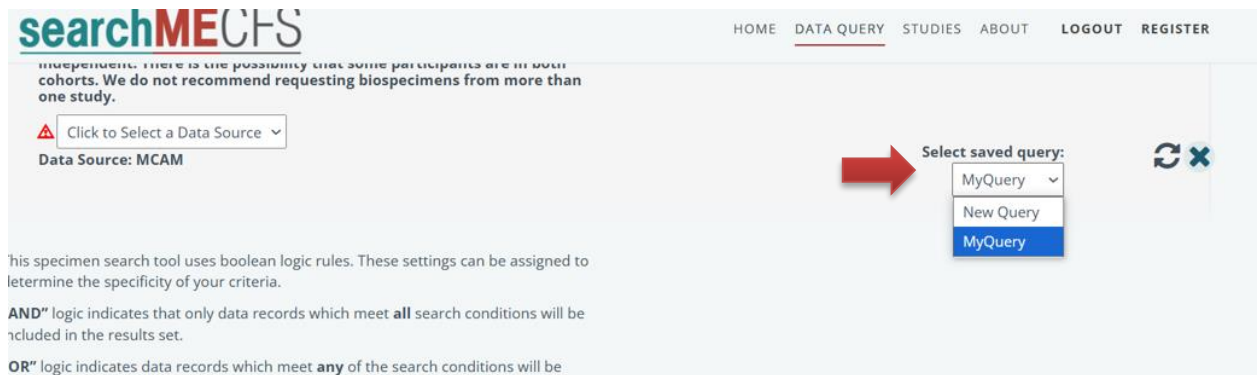

A query name must:

- Contain at least one non-space character
- Be unique to the user who is saving it

If you enter an existing query name, the Save Query button will not enable.

4.2.7   Retrieving Queries

You can retrieve saved queries by clicking on the Query dropdown list in the upper right corner of the query page. The Query list defaults to the New Query option.

You can retrieve saved queries by clicking on the Query dropdown list in the upper right corner of the query page and selecting a displayed Saved query. The Query list defaults to the New Query option.

- Selecting a saved query will only populate the search bar with the saved search criteria. The user must click Search to execute the saved query.

- A saved query only saves search criteria. It does *not* save search results. Because the available quantity of biospecimens may change (e.g. as additional requests are fulfilled), it is possible that the same query executed at different times may return different results.

- The Saved Query list consists only of queries saved by the current user. Users cannot see queries saved by other users.

4.2.8   Deleting Saved Queries

You can delete a Saved query by selecting that query and clicking the Delete Query button – the X icon to the right of the Saved Query dropdown list. If the Query list is displaying the New Query option, the Delete Query button is disabled.

4.2.9   Resetting Queries

You can reset the search bar by:

- Selecting New Query from the Saved Query dropdown list; or

- Clicking the Reset Query button in the top right area of the search bar.

Resetting a query has no impact on Saved queries.
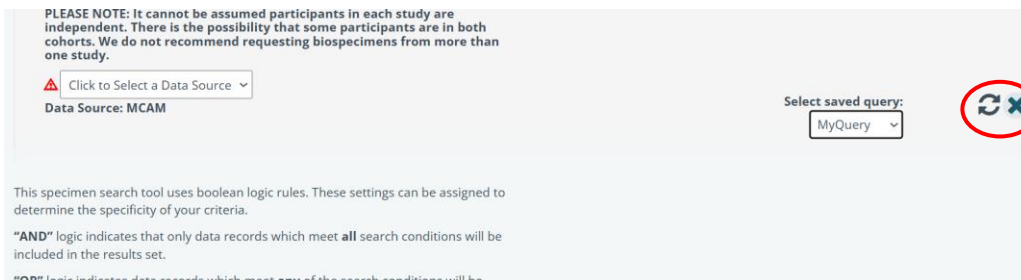
4.2.10   Exporting Query Results

You can export your query results to a .csv file by clicking the Export Results to CSV button on the Query Results page. The export contains all the data displayed on the Query Results page.

5. Query Examples

Example 1: Simple Query with one search criterion

Suppose you are looking for **biospecimens from all female MCAM study participants (i.e., ME/CFS cases and controls)**

- Choose a data source

- Select a Query Category

- Select a Criterion

- Select a logical condition

- Select a target value

- Click Search. The system displays details about the Participants who match your search criteria and their specimens.

Query Results

Data_Source="MCAM" AND (Biologic_Sex = "Female")

Found **3002** specimens from **559** participants.

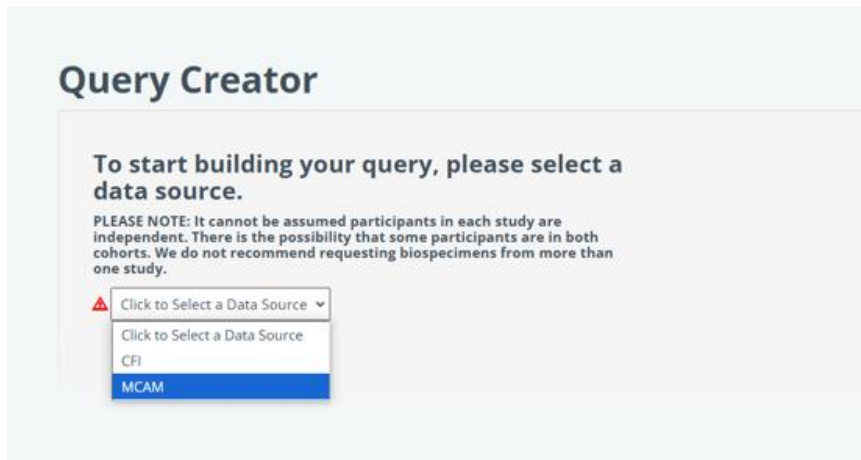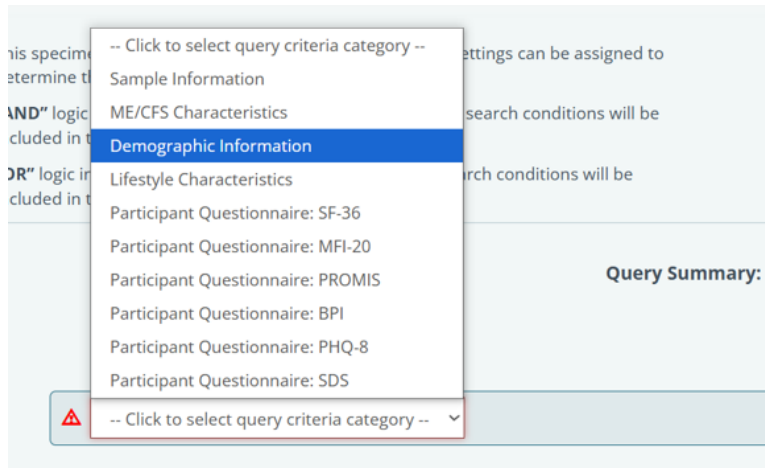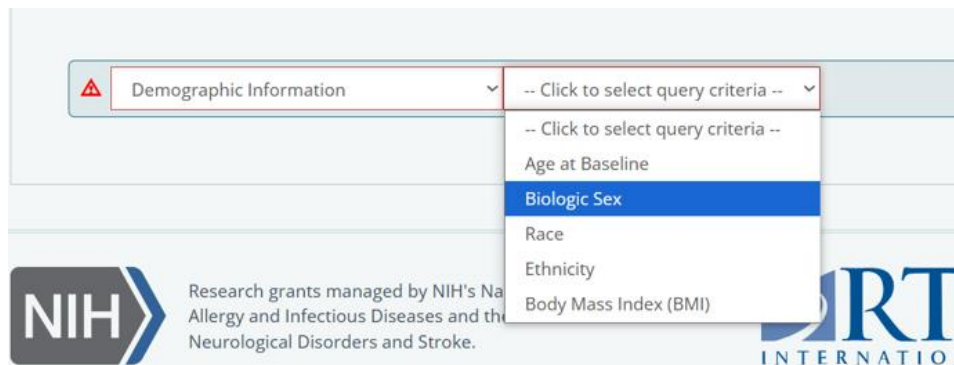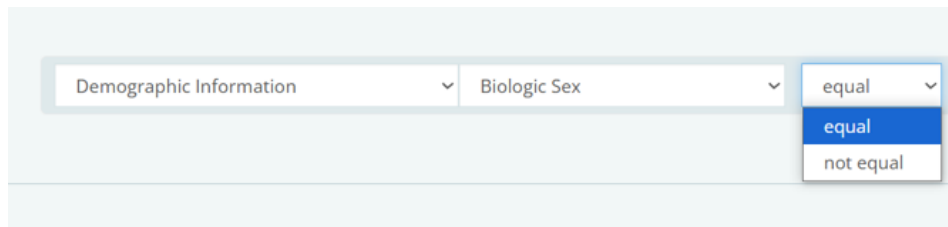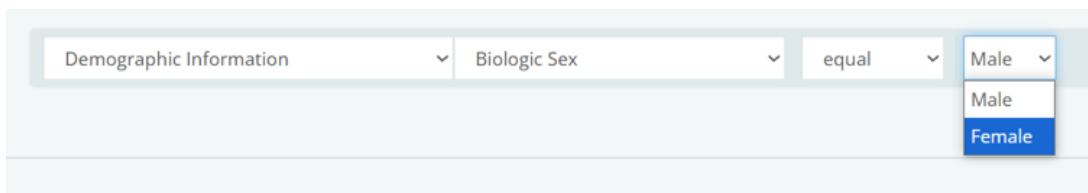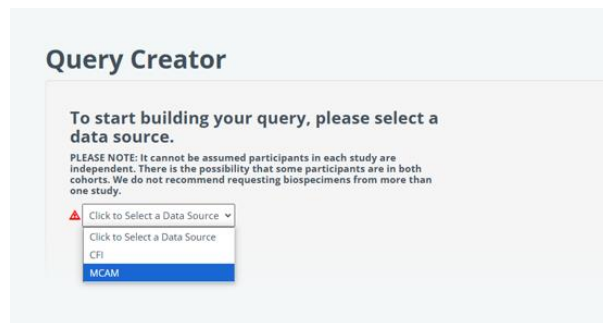Apply for access to the biospecimens through NINDS   Export Results to CSV

PARTICIPANT ID	ME/CFS CHARACTERISTICS	SEX	AGE	SPECIMEN TYPE	SPECIMEN QUANTITY	AVAILABLE INVENTORY	SALIVA COLLECTION TIMEPOINT
720143	Control Participant	Female	63	DNA	453 ug	1	n/a
720143	Control Participant	Female	63	Plasma	10 mL	1	n/a
720143	Control Participant	Female	63	Saliva	250 uL	1	Awakening
720143	Control Participant	Female	63	Saliva	250 uL	1	30 Minutes Post-Awakening

Example 2. Simple Query with multiple search criteria

Suppose you are looking for **biospecimens** from all **female MCAM participants with ME/CFS (i.e., ME/CFS cases).**

- Choose a data source

Query Creator

To start building your query, please select a data source.

PLEASE NOTE: It cannot be assumed participants in each study are independent. There is the possibility that some participants are in both cohorts. We do not recommend requesting biospecimens from more than one study.

⚠ Click to Select a Data Source ⌄
Click to Select a Data Source
CFI
MCAM

- Select a Query Category

This specimen search tool uses boolean logic rules. These s
determin
-- Click to select query criteria category --

"AND" lo   Sample Information   all
included   ME/CFS Characteristics

"OR" log Demographic Information   se
included   Lifestyle Characteristics

          Participant Questionnaire: SF-36
          Participant Questionnaire: MFI-20
          Participant Questionnaire: PROMIS   ata
          Participant Questionnaire: BPI
          Participant Questionnaire: PHQ-8
          Participant Questionnaire: SDS

Demographic Information   ⌄

- Select a Criterion

- Select a logical condition

- Select a target value

- ADD CRITERION to include additional query criteria and target values. Ensure 'AND' is selected.
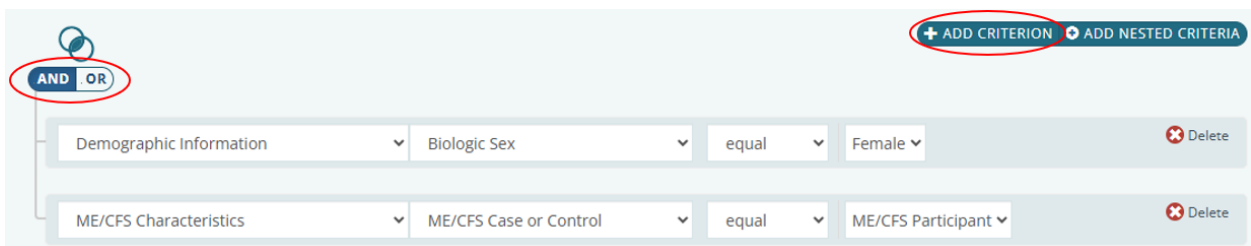
- Click Search. The system displays details about the Participants who match your search criteria and their specimens.

Query Results

Data_Source="MCAM" AND (Biologic_Sex = "Female" AND ME/CFS_Case_or_Control = "ME/CFS Participant")

Found **1751** specimens from **333** participants.

Apply for access to the biospecimens through NINDS   Export Results to CSV

PARTICIPANT ID	ME/CFS CHARACTERISTICS	SEX	AGE	SPECIMEN TYPE	SPECIMEN QUANTITY	AVAILABLE INVENTORY	SALIVA COLLECTION TIMEPOINT
746030	ME/CFS Participant	Female	67	DNA	318 ug	1	n/a
746030	ME/CFS Participant	Female	67	RNA	35.995 ug	1	n/a
746030	ME/CFS Participant	Female	67	Plasma	10 mL	1	n/a
746030	ME/CFS Participant	Female	67	Saliva	150 uL	1	Awakening

Example 3. Complex Query with nested group search criteria

This example selects two possible values for a single variable. This involves using a Nested Query. Suppose you are looking **for DNA and RNA specimens from all female MCAM participants with ME/CFS**.
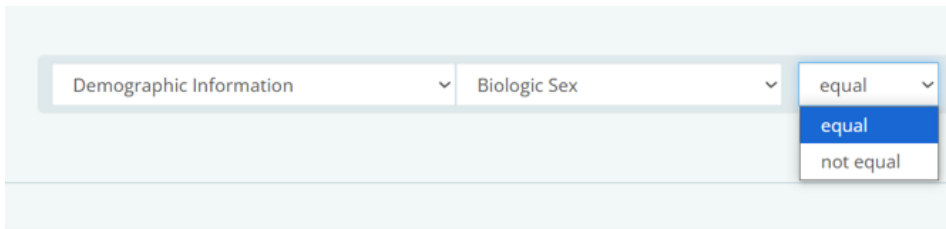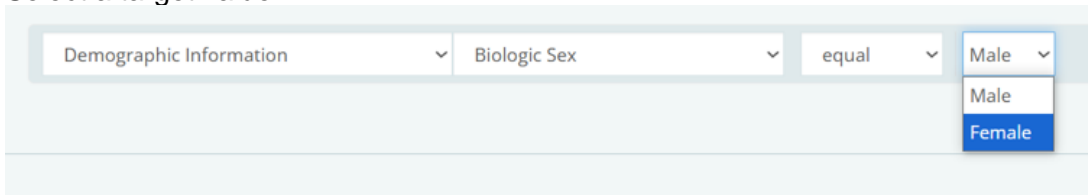
- Repeat the steps from example 2.

- Click Add Nested Criteria. A new row appears to specify a new condition. Note that the new row is indented. The indentation denotes nested criteria.

- Select the desired search criteria (e.g., Sample Type is DNA)

- Click Add Criterion and repeat the previous step within the Nested Criteria to add more filter criteria (e.g., Sample Type is RNA).

  Ensure 'OR' is selected within the nested criteria. You must use OR here because you are searching for each sample that is DNA or RNA. Using AND here would search for samples that are both DNA and RNA, which do not exist.

- Click Search. The system displays the ME/CFS Participants and their specimens matching your search criteria. The system evaluates the nested criteria first, then applies the additional filters to that results set for a final result set. This example displays all DNA and RNA samples from female MCAM ME/CFS participants (ME/CFS cases). The query summary is displayed at the top of the Query Results table.

Query Results

Data_Source="MCAM" AND (Biologic_Sex = "Female" AND ME/CFS_Case_or_Control = "ME/CFS Participant" AND (Sample_Type = "DNA" OR Sample_Type = "RNA"))

Found **535** specimens from **333** participants.

Apply for access to the biospecimens through NINDS   Export Results to CSV

PARTICIPANT ID	ME/CFS CHARACTERISTICS	SEX	AGE	SPECIMEN TYPE	SPECIMEN QUANTITY	AVAILABLE INVENTORY	SALIVA COLLECTION TIMEPOINT
746030	ME/CFS Participant	Female	67	DNA	318 ug	1	n/a
746030	ME/CFS Participant	Female	67	RNA	35.995 ug	1	n/a
749413	ME/CFS Participant	Female	54	DNA	105 ug	1	n/a
749531	ME/CFS Participant	Female	23	DNA	383 ug	1	n/a
749898	ME/CFS Participant	Female	20	DNA	13 ug	1	n/a

You can edit your query at any time by changing the selected variables, logical conditions or target values and clicking Search to update your search results.

Feel free to contact the searchMECFS support team at searchMECFS@rti.org any time for assistance with query building.

6. How to request biospecimens

When you have found the samples of interest, click the "Apply for access to the biospecimens through NINDS" link at the top of the Query Results table. This will take you to the NINDS BRAC Application page, which has instructions and document links to enable you to request the biospecimens of interest. Note that the BRAC Application page and linked documents are owned and managed by the NINDS.

Query Results

Data_Source="MCAM" AND (Biologic_Sex = "Female" AND ME/CFS_Case_or_Control = "ME/CFS Participant" AND (Sample_Type = "DNA" OR Sample_Type = "RNA"))

Found **535** specimens from **333** participants.

Apply for access to the biospecimens through NINDS   Export Results to CSV

PARTICIPANT ID	ME/CFS CHARACTERISTICS	SEX	AGE	SPECIMEN TYPE	SPECIMEN QUANTITY	AVAILABLE INVENTORY	SALIVA COLLECTION TIMEPOINT
746030	ME/CFS Participant	Female	67	DNA	318 ug	1	n/a
746030	ME/CFS Participant	Female	67	RNA	35.995 ug	1	n/a
749413	ME/CFS Participant	Female	54	DNA	105 ug	1	n/a
749531	ME/CFS Participant	Female	23	DNA	383 ug	1	n/a
749898	ME/CFS Participant	Female	20	DNA	13 ug	1	n/a