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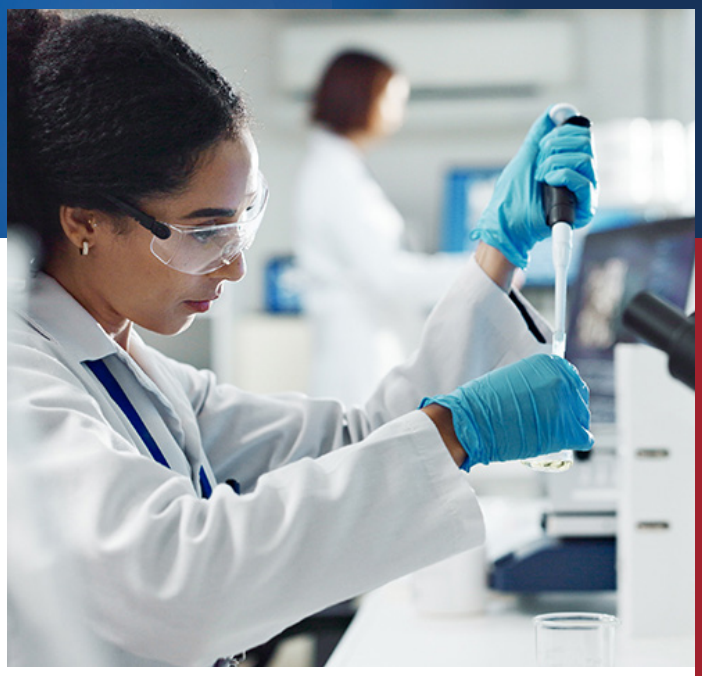

searchMECFS: An Online, Interactive Platform to Facilitate Secondary Use of Biospecimens and Associated Research Data From Myalgic Encephalomyelitis Studies

Quinn Barnette, Keith LeGrow, Michael Ham, Dóra Illei, Stephanie N. Giamberardino, Megan U. Carnes, and Linda M. Brown

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Contents

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Abstract

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex, debilitating disease affecting multiple body systems, with no established biomarkers for diagnosis or treatment. This publication introduces searchMECFS, a free, interactive online platform developed by the Data Management and Coordinating Center of the ME/CFS Research Network, with funding from the National Institutes of Health. The platform's purpose is to facilitate the secondary use of biospecimens and associated research data from ME/CFS clinical studies by improving accessibility, visibility, and sharing of these resources. Currently, searchMECFS facilitates access to biospecimens and associated data from two studies: The Chronic Fatigue Initiative study, funded by the Hutchins Family Foundation, and the Multi-Site Clinical Assessment of ME/CFS study, funded by the Centers for Disease Control and Prevention. Users can query participant demographics and clinical information and request available biospecimens through an application process. Eight specimen types are currently available, though availability varies by study. The results highlight a case where a researcher used the searchMECFS platform to identify 40 serum samples, which contributed to published research on circadian rhythm disruption in ME/CFS. searchMECFS aims to accelerate scientific discovery within the ME/CFS research community by improving biospecimen utilization, fostering data sharing, and supporting collaboration.

Background

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex and debilitating disease of unknown etiology that is estimated to affect approximately 1.3% of adults (about 3.3 million individuals) in the United States.[1] ME/CFS is characterized by substantial functional impairment accompanied by severe fatigue, cognitive impairment, unrefreshing sleep, orthostatic intolerance, and post-exertional malaise.[2-4] Although the etiology of the disease remains unknown, numerous studies support the hypothesis that ME/CFS may be triggered by a viral infection,[5-9] including recent evidence suggesting that the risk of developing ME/CFS increases following SARS-CoV-2 infection.[10] Studies have shown that ME/CFS is associated with irregularities across multiple body systems, including disruptions in immune function, protein signaling, metabolism, and gene expression.[11-16] Although several potential biomarkers for ME/CFS have been investigated, none have been validated for reliably distinguishing individuals with ME/CFS from healthy controls in clinical settings.[17] In addition, there are currently no treatments for ME/CFS approved by the U.S. Food and Drug Administration, though experienced clinicians have reported off-label use of several therapies that appear to benefit many patients.[18]

Investigators with hypotheses relevant to ME/CFS can benefit from access to a biorepository of biospecimens and associated data from individuals with ME/CFS and matched healthy controls. Despite the number of individuals with this debilitating disease, few ME/CFS-specific biorepository resources exist.[19-22] Although large volumes of biospecimens are often collected across ME/CFS and other research settings, many remain unused because of limited visibility and coordinated infrastructure to support investigator access.[23, 24] This underutilization has been identified as an ethical concern, reflecting a responsibility to ensure that collected specimens and associated data are used for scientific and public benefit.[25] Facilitating secondary use of existing biospecimens and associated data is therefore essential to maximizing scientific value for ME/CFS research while streamlining the research process, reducing costs, and accelerating the pace of discovery.[26] Recognizing these challenges and opportunities, the ME/CFS Research Network's[27] Data Management and Coordinating Center (DMCC) at RTI International developed searchMECFS,[28] a free, interactive online resource to facilitate secondary use of ME/CFS biospecimens and associated data. searchMECFS supports the ME/CFS research community by enabling researchers to query two U.S. government–funded ME/CFS biorepositories using available demographic, clinical, and biospecimen data in order to assess the availability of biospecimens in support of their research.

Methods

Overview and Technical Design

In 2017, multiple institutes within the National Institutes of Health funded the ME/CFS Research Network,[27] comprising three Collaborative Research Centers and a DMCC to advance ME/CFS research. The goal of the Network is to strengthen collaborative research and promote data sharing to improve the understanding of ME/CFS diagnosis and treatment. The DMCC developed two complementary data-sharing tools that use de-identified data: searchMECFS,[28] an online ME/CFS biospecimen search resource, and mapMECFS,[29] an interactive data portal that provides access to results across many biological disciplines from research focused on advancing our understanding of ME/CFS. searchMECFS enables researchers to identify and request available biospecimens and associated data for laboratory analyses, and the corresponding full clinical datasets are maintained in mapMECFS.[28] searchMECFS was designed to let researchers use query results for initiating applications to the National Institute of Neurological Disorders and Stroke (NINDS) Biospecimen Resource Access Committee (BRAC), an external scientific review panel, to request biospecimens of interest free of charge. In-depth clinical data associated with these biospecimens are then made available to BRAC-approved researchers through mapMECFS.

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searchMECFS System Design

searchMECFS is securely hosted on the Microsoft Azure App Service cloud platform. The site's intuitive design allows researchers to search for available biospecimens based on sample type and participant characteristics. To accomplish this, the user interface and query functionality are built on a base of .NET Core 2.1[30] with WebAPI. It integrates the use of HTML 5, JavaScript, Typescript, jQuery v3.3.1,[31] and jQuery UI v1.12.1[32] and leverages the Bootstrap front-end framework v3.4.1.[33] To ensure privacy and confidentiality, all system data are stored in a Microsoft SQL Server database,[34] with encryption at rest implemented as a key security measure to prevent unauthorized access in case of system breaches. The searchMECFS hosting platform is fully compliant with the security and regulatory standards defined in Federal Information Processing Standard 199,[35] as set forth in the Federal Information Security Modernization Act of 2014.[36]

Data are stored in database tables optimized for use by the searchMECFS system, enabling efficient querying and retrieval of biospecimen inventory. The query tool, built on v2.5.2 of the jQuery QueryBuilder plugin,[37] allows users to construct customized searches through an intuitive interface. As users build queries, the system generates a human-readable, exportable query statement to help users understand their search structure and results. Query search results are exportable as comma-separated values (CSV) files to facilitate further analysis. To ensure up-to-date and accurate inventory information, sample inventory data are securely transferred from the appropriate biorepositories and updated following each fulfilled request.

Participating Studies

searchMECFS currently hosts biospecimen and select clinical data from two studies: the Chronic Fatigue Initiative (CFI) Study[38] and the Multi-Site Clinical Assessment of ME/CFS (MCAM).[39] Both studies recruited individuals with ME/CFS and healthy controls, used standardized questionnaires to assess overall functioning and ME/CFS symptoms, and collected biospecimens for future hypothesis testing.

Chronic Fatigue Initiative Study

The CFI Study was established and funded by the Hutchins Family Foundation to advance research into the underlying causes of ME/CFS.[40] As part of the initiative, individuals with ME/CFS and healthy controls from five U.S. clinical research sites specializing in ME/CFS clinical care were recruited between 2011 and 2013 to participate in the CFI Study.[38] The study participants with ME/CFS were aged 18 to 65 years, were diagnosed by a healthcare provider with expertise and experience with ME/CFS, and met at least one of two ME/CFS case definitions: 1994 Fukuda Criteria[41] or Canadian Criteria.[42,43] Healthy controls were aged 18 to 65 years; had no history of ME/CFS or other active illnesses; and were age-, sex-, and geographic location-matched to the ME/CFS study participants.[38]

Multi-Site Clinical Assessment of ME/CFS

The MCAM study was conducted in multiple stages by the Centers for Disease Control and Prevention (CDC), in collaboration with ME/CFS specialty clinics, from 2012 to 2020.[39,44] It was conducted in two major components: (1) an adult longitudinal cohort, and (2) a pediatric longitudinal cohort. The adult cohort also included cognition and exercise testing substudies.[45,46] The adult longitudinal cohort recruited individuals aged 18 to 70 years at their baseline enrollment who had been diagnosed with ME/CFS or post-infectious fatigue or were being managed for ME/CFS by an expert physician. The ME/CFS study participants were not required to fit a specific case definition to be eligible. Healthy controls were participants aged 18 to 70 years with no history of ME/CFS or other active illnesses who were age- and sex-matched to the ME/CFS participants.[39] During Stage 1 of the study, investigators only enrolled participants with ME/CFS. In subsequent stages, investigators collected follow-up information from those enrolled in Stage 1 and started recruiting healthy controls, as well as newly enrolled ME/CFS participants. Because enrollment happened in multiple stages, each participant's first study visit could come from any stage of the study. Biospecimens and clinical data were collected at multiple study visits, enabling longitudinal evaluation of participants.[39] The pediatric longitudinal cohort

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took place from 2013 to 2020 at four ME/CFS clinics, recruited individuals aged 10 to 17 years, and followed methods similar to those described for the adult longitudinal cohort, but with age-appropriate instruments.

Data De-Identification and Sharing

searchMECFS data-sharing procedures are designed to protect the privacy of all study participants. CFI study participants who provided informed consent for the original study and did not opt out after being notified of the transfer of their biological samples and health data to NINDS were included in data shared on searchMECFS. Similarly, MCAM study participants who consented to sample storage for future research in the original study were included. NINDS and CDC officials were required to sign a Data Use Agreement (DUA) and Data Submitter Agreement to share data on searchMECFS and mapMECFS. NINDS and CDC assigned a de-identified identification number (ID) to each study participant prior to sharing their data with the DMCC. In addition, there are no links directly connecting the biospecimens with a participant's identity. All clinical data shared on searchMECFS adhere to the "safe harbor" approach to the Health Insurance Portability and Accountability Act for removal of 18 potential participant identifiers.[47] searchMECFS users must sign a DUA during registration agreeing to comply with data access and usage restrictions.[48]

Results

Currently, searchMECFS hosts biospecimen information and associated clinical data from two ME/CFS research studies. searchMECFS began hosting biospecimen and clinical data from the CFI Study in 2019 and from the MCAM study in 2024. The demographic characteristics of these studies are outlined in **Table 1**.

Table 1. Demographic characteristics of individuals with ME/CFS and healthy controls from CFI and MCAM Adult and MCAM Pediatric studies at first study visit

Characteristic	CFI		MCAM Adult		MCAM Pediatric	
	ME/CFS (*n* = 201)	Controls (*n* = 200)	ME/CFS (*n* = 459)	Controls (*n* = 343)	ME/CFS (*n* = 40)	Controls (*n* = 37)
Median age (IQR)	49 (39, 58)	50 (38, 56)	51 (40, 58)	46 (28, 55)	16 (14, 17)	13 (12, 15)
Sex, *n* (%)						
Female	143 (71%)	143 (72%)	333 (73%)	226 (66%)	21 (53%)	21 (57%)
Male	58 (29%)	57 (29%)	126 (27%)	117 (34%)	19 (48%)	16 (43%)
Race, *n* (%)						
White	196 (98%)	190 (95%)	395 (86%)	177 (52%)	30 (75%)	33 (89%)
Black/African American	1 (0.5%)	3 (1.5%)	9 (2.0%)	21 (6.1%)	0 (0%)	0 (0%)
Other	1 (0.5%)	2 (1.0%)	23 (5.0%)	93 (27%)	7 (18%)	1 (2.7%)
Missing	3 (1.5%)	5 (2.5%)	32 (7.0%)	52 (15%)	3 (7.5%)	3 (8.1%)
Ethnicity, *n* (%)						
Non-Hispanic	186 (93%)	184 (92%)	363 (79%)	179 (52%)	31 (78%)	33 (89%)
Hispanic	15 (7.5%)	16 (8.0%)	27 (5.9%)	95 (28%)	1 (2.5%)	0 (0%)
Missing	0 (0%)	0 (0%)	69 (15%)	69 (20%)	8 (20%)	4 (11%)
Employment, *n* (%)						
Employed	34 (17%)	128 (64%)	103 (22%)	224 (65%)	–	–
Not employed/Not working	167 (83%)	71 (36%)	300 (65%)	85 (25%)	–	–

continued...

Characteristic	CFI		MCAM Adult		MCAM Pediatric	
	ME/CFS (*n* = 201)	Controls (*n* = 200)	ME/CFS (*n* = 459)	Controls (*n* = 343)	ME/CFS (*n* = 40)	Controls (*n* = 37)
Missing	0 (0%)	1 (0.5%)	56 (12%)	34 (9.9%)	–	–
Insured, *n* (%)						
Yes	191 (95%)	167 (84%)	413 (90%)	259 (76%)	36 (90%)	24 (65%)
No	8 (4.0%)	30 (15%)	20 (4.4%)	61 (18%)	0 (0%)	6 (16%)
Don't know	1 (0.5%)	1 (0.5%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Refuse to answer	1 (0.5%)	2 (1.0%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)
Missing	0 (0%)	0 (0%)	26 (5.7%)	23 (6.7%)	4 (10%)	7 (19%)
Education, *n* (%)						
Less than HS, HS graduate, GED, some college	44 (22%)	61 (31%)	101 (22%)	100 (29%)	–	–
College graduate	90 (45%)	90 (45%)	176 (38%)	120 (35%)	–	–
Post-college	61 (30%)	49 (25%)	151 (33%)	98 (29%)	–	–
Refuse to answer	5 (2.5%)	0 (0%)	0 (0%)	0 (0%)	–	–
Missing	1 (0.5%)	0 (0%)	31 (6.8%)	25 (7.3%)	–	–

CFI = Chronic Fatigue Initiative; HS = high school; IQR = interquartile range; MCAM = Multi-Site Clinical Assessment of ME/CFS; ME/CFS = myalgic encephalomyelitis/chronic fatigue syndrome; NA = not available.

Biospecimen Availability

Details of biospecimen collection and storage have been described elsewhere for both studies.[38,39] The CFI Study collected specimens from 401 participants, including 201 individuals with ME/CFS and 200 healthy controls. The study collected DNA, RNA, plasma, saliva, serum, urine, peripheral blood mononuclear cells, and tears from all consenting participants. All samples were collected at the first clinical study visit.[38] CFI biospecimens were originally housed at Duke University before being transferred to the NINDS-supported biorepository, BioSEND, at Indiana University.[49]

searchMECFS hosts biospecimen data from multiple components of the MCAM study: (1) two study visits from the adult longitudinal cohort, (2) one study visit from the adult cohort cognition and exercise substudies, and (3) one study visit from the pediatric longitudinal cohort. For Visit 1 of the adult cohort, samples were collected from 801 participants (459 ME/CFS cases and 343 healthy controls).[39] Visit 2 was conducted approximately 10–14 months after Visit 1 and included specimens from 501 participants (346 ME/CFS cases and 155 healthy controls).[39] Whole blood, plasma, and saliva were collected during all study visits, and DNA and RNA were isolated from the whole blood samples.[39] All samples were collected during a clinical study visit except for saliva, which was collected at four time points (0, 30, 45, and 60 minutes post-waking) at the participant's home using saliva collection kits.[39] An additional study visit is available for a subset of 426 adult participants (261 ME/CFS cases and 165 healthy controls) who participated in the cognition and exercise substudies.[45,46] It should be noted that most of these participants are also enrolled in the adult longitudinal cohort, though some are not. Among these substudy participants, pre- and post-testing plasma samples are available. One study visit is currently available for the MCAM pediatric cohort. For this cohort, saliva samples are available from 54 participants (25 ME/CFS cases and 29 healthy controls) at the same post-waking time points used in the adult cohort. All MCAM biospecimens are stored in a CDC biorepository.

Because biospecimen availability varies dynamically by phenotype, visit, and prior distribution, detailed sample counts are best assessed through the searchMECFS query interface, which allows investigators to identify specimens that meet specific

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criteria. In addition, CFI and MCAM biospecimens are stored in separate repositories, resulting in slight differences in their aliquot preparation and shipping procedures. Current storage aliquot sizes and example aliquot sizes for distribution are summarized in **Table 2**.

Search Parameters for Biospecimen Queries

Participant demographics, select clinical data, and responses to ME/CFS symptom questionnaires can be used as search parameters to refine biospecimen queries. These data elements are grouped into domains of ME/CFS illness characteristics and timing, demographics, lifestyle characteristics, and participant questionnaires. Data from questionnaires that measure patient-reported outcomes of ME/CFS symptoms, quality of life, and well-being are presented as questionnaire-specific summary subscores. Documentation of questionnaire scoring and data modifications is available for download on searchMECFS, along with associated data dictionaries. **Table 3** summarizes the questionnaires available for both MCAM and CFI as biospecimen search parameters. This does not represent an exhaustive list of instruments used in each study but includes those available as searchable parameters in the biospecimen query tool.

Example Query Results

searchMECFS provides an intuitive interface for researchers to independently perform complex queries and determine the availability of biospecimens. Users can filter by selected search parameters, as described above, to assess available specimens and quantities from respective biorepositories. Flexible grouping of search parameters allows for tailored, detailed queries. An example query for ME/CFS samples from the CFI Study is shown in the **Supplemental Information Figure S1**. Query results, provided as an exportable CSV file, include a standard set of output variables, including a de-identified participant ID, case/control status, sex, age, specimen types, and available specimen quantities. These results can be submitted with applications to the NINDS BRAC to request biospecimens of interest.

Requesting Biospecimens Using searchMECFS

The workflow to query for biospecimens using searchMECFS and request those of interest is summarized in **Figure 1**. Researchers interested in requesting biospecimens must register on searchMECFS, complete a registration form, and agree to the terms outlined in the searchMECFS

Table 2. Summary of CFI and MCAM biospecimen suggested aliquot volumes and collection time points

	CFI			MCAM		
Sample	Current aliquot size	Suggested aliquot size	Collection time	Current aliquot size*	Suggested aliquot size	Collection time
DNA	25 µg	3 µg	Study visit	250 µL aliquots (Mean: 52.3 µg; Range: 1.75–452.3 µg)	1–3 µg	Study visit
RNA	1 µg	1 µg	Study visit	15 µL aliquots (Mean: 2.9 µg; Range: 0.014–21.0 µg)	0.5–1 µg	Study visit
Plasma	100 or 250 µL	100 or 250 µL	Study visit	2 mL	100 or 250 µL	Study visit
Saliva	1 mL	NA	Study visit	Mean: 790 µL Range: 100 µL–2000 µL	100 or 250 µL	0, 30, 45, 60 min post-waking
Serum	100 or 250 µL	100 or 250 µL	Study visit	NA	NA	NA
Urine	1 mL	1 mL	Study visit	NA	NA	NA
PBMC	5×10^6 cell/1mL	NA	Study visit	NA	NA	NA
Tears	1 mL	1 mL	Study visit	NA	NA	NA

CFI = Chronic Fatigue Initiative; MCAM = Multi-Site Clinical Assessment of ME/CFS; NA; = not available/not collected; PBMC = peripheral blood mononuclear cells.

**MCAM samples are re-aliquoted by the Centers for Disease Control and Prevention to provide enough material to the investigator to avoid undue depletion of the inventory.*

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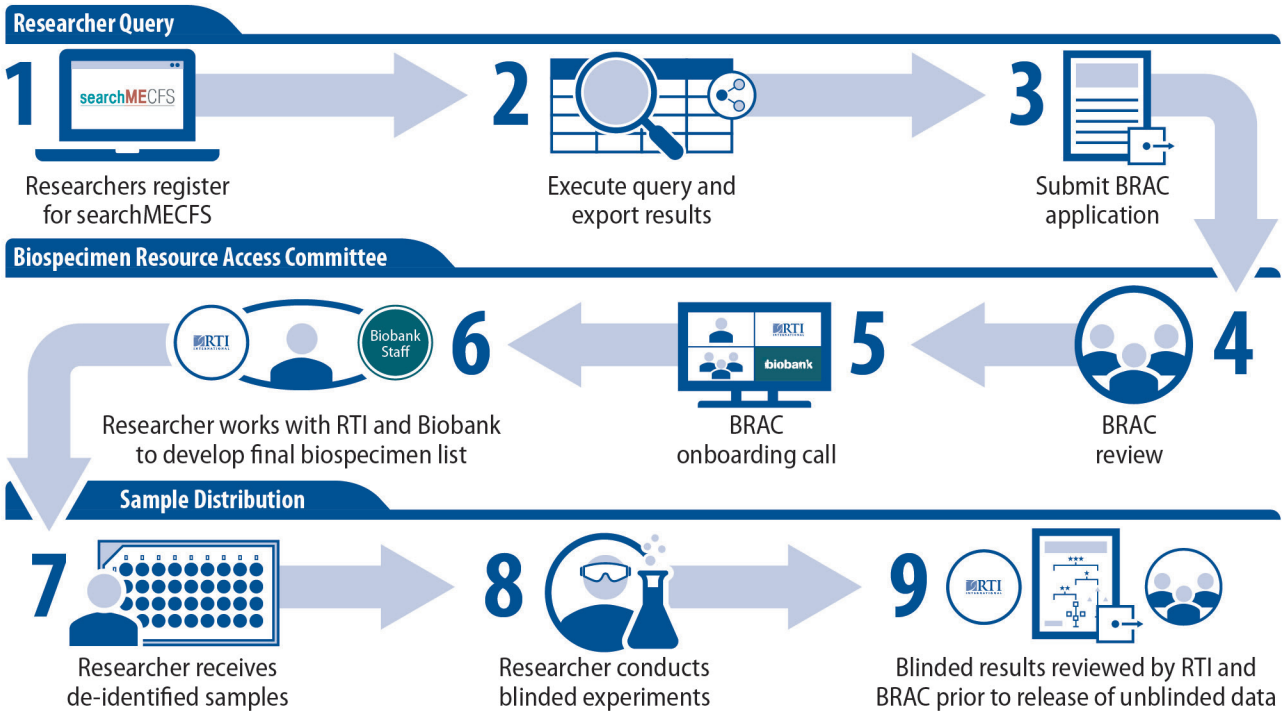
Table 3. Questionnaires available on searchMECFS for use as biospecimen search parameters

Questionnaire	Description	Study
Medical Outcomes Study 36-Item Short Form Survey (SF-36)[50]	Self-reported indicator of general quality of life. It measures eight domains of well-being, including physical health to social activity.	CFI, MCAM
20-item Multidimensional Fatigue Inventory (MFI-20)[51]	Self-reported indicator of fatigue. It measures five dimensions of fatigue: general fatigue, physical fatigue, mental fatigue, reduced motivation, and reduced activity.	CFI, MCAM
Brief Pain Inventory (BPI)[52]	Self-reported measure of location and intensity of pain and interference with daily activities.	CFI, MCAM
DePaul Symptom Questionnaire (DSQ)[43]	Assessment of the occurrence, frequency, and intensity of symptoms common in ME/CFS.	CFI
Beck Depression Inventory (BDI)[53]	Self-reported 21-item survey that measures symptoms and characteristics of depression, including mood and physical symptoms like fatigue and sleep disturbances.	CFI
Beck Anxiety Inventory (BAI)[54]	Self-reported 21-item survey that measures occurrence and severity of anxiety symptoms. Respondents rate how much they have been bothered by each symptom over the past month on a scale from 0 (not at all) to 3 (severely).	CFI
Pittsburgh Sleep Quality Index (PSQI)[55]	Self-reported 19-item survey designed to assess sleep quality over a 1-month period. Evaluates seven domains of sleep quality: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleep medication, and daytime dysfunction.	CFI
Patient-Reported Outcomes Measurement Information System (PROMIS) Short Form[56]	Self-reported measures of general physical, mental, and social health. Specific domains evaluated include fatigue, sleep, and pain.	MCAM
8-item Patient Health Questionnaire depression scale (PHQ-8)[57,58]	Self-reported 8-item measure of depressive symptoms.	MCAM
Self-Rating Depression Scale (SDS)[59]	Measures 20 items related to severity of current depression symptoms.	MCAM

Figure 1. Workflow diagram for requesting biospecimens using searchMECFS



BRAC = Biospecimen Resource Access Committee.

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DUA. The registration is reviewed and approved by the DMCC. Once a registration is approved, researchers can access searchMECFS to select a study of interest (i.e., CFI, MCAM) and use search parameters to query biospecimen availability. After identifying suitable biospecimens, researchers can submit an application to the NINDS BRAC through the BioSEND website.[49]

The BRAC evaluates applications based on the experimental rationale, assay feasibility and reproducibility, the investigator's expertise, institutional resources and funding available to support the study, and the statistical analysis and scientific justification of the sample size needed for hypothesis testing. Approved applicants participate in a virtual onboarding meeting to finalize sample selection, preparation, and shipping logistics. Biospecimens that are de-identified and blinded to case/control status are then distributed to researchers by the relevant biorepository. After completing initial blinded experiments, researchers share these data with the DMCC and NINDS program staff for review to document assay completion before receiving the sample unblinding file. Researchers are required to upload the final results of their study to mapMECFS[29] to promote data sharing within the broader research community.

Case Study

To demonstrate the utility of searchMECFS, we highlight a 2023 study where secondary use of biospecimens and associated data were used to examine cellular circadian rhythm disruption in ME/CFS.[60] The researcher used searchMECFS to identify 40 serum samples (20 ME/CFS cases and 20 controls) from the CFI Study that satisfied the following inclusion criteria based on available clinical data: participants aged 18 to 65 years, a primary infection-related onset of ME/CFS, a diagnosis of ME/CFS by a healthcare provider, and a Pittsburgh Sleep Quality Index sleep severity score of greater than 6. The study demonstrated that circadian rhythm in peripheral cells may be impacted by ME/CFS serum factors and symptoms related to ME/CFS, such as insomnia.[60]

Discussion

Although large numbers of biospecimens have been collected for ME/CFS research, improving their visibility and accessibility for secondary use represents a significant opportunity to expand scientific impact and accelerate discovery. searchMECFS advances this opportunity by making existing ME/CFS biospecimens and associated data more discoverable and accessible to investigators. searchMECFS facilitates secondary use of ME/CFS biospecimens and associated data by (1) hosting data from two large ME/CFS cohorts (CFI and MCAM); (2) offering researchers a centralized resource to query biospecimen data using participant demographics and questionnaires that measure patient-reported outcomes of ME/CFS symptoms, quality of life, and well-being; (3) providing flexible and intuitive search parameters that let investigators identify suitable biospecimens for hypothesis-driven research; (4) facilitating applications to NINDS BRAC for access to biospecimen resources free of charge; and (5) promoting sharing of experimental data with the broader research community through mapMECFS.

Because searchMECFS hosts biospecimens from multiple studies, there are some limitations to consider. First, it is possible that some participants were enrolled in more than one study, and participant overlap cannot be assessed. Thus, to avoid inadvertent duplication of participants in analyses, requesting biospecimens from more than one study is not recommended. In addition, the CFI and MCAM studies used different symptom assessments and diagnostic criteria, so any cross-study comparisons should be interpreted with caution.

searchMECFS was successfully used to request ME/CFS biospecimens for original research, which generated novel insights into potential biological mechanisms underlying ME/CFS symptoms.[60] The site's well-characterized inventory of biospecimens has the potential to support a variety of hypothesis-driven projects from early-career investigators to established researchers. searchMECFS is available to the scientific community with registration, as described above. ME/CFS researchers are encouraged

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to explore searchMECFS and identify biospecimens that align with their study needs. The DMCC plans to expand sample availability in the future, including additional MCAM biospecimens and clinical data.

Conclusion

searchMECFS enables investigators to independently identify well-characterized biospecimens and associated demographic and clinical data from ME/CFS studies. By simplifying the biospecimen discovery and application process, this resource supports novel ME/CFS research, encourages resource sharing and collaboration within the ME/CFS research community, and facilitates secondary use of valuable ME/CFS bioresources. Improved visibility and accessibility through searchMECFS will help maximize the scientific value of existing ME/CFS biospecimens. We invite investigators to visit the searchMECFS website and explore available samples to support their research.

Data Availability Statement

The searchMECFS biospecimen search tool is open to the research community at https://searchmecfs.org/.

Authors' Contributions

Quinn Barnette and Keith LeGrow led the writing of this work. Mr. Barnette and Michael Ham are the data management and development leads for searchMECFS. Dóra Illei and Stephanie N. Giamberardino are technical staff working on the development of searchMECFS. Linda M. Brown and Megan U. Carnes are the co–Principal Investigators on the ME/CFS DMCC and advised the development of searchMECFS. All authors edited and reviewed the manuscript.

Supplementary Information

An example searchMECFS query output for the CFI Study is provided in the Supplementary Information Figure S1: https://doi.org/10.5281/zenodo.22132889.

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