

Managed by **Duke** Clinical & Translational Science Institute

The MURDOCK Study Community Registry and Biorepository is a 12,526-participant community-based longitudinal cohort recruited from a 20-Zip Code region in the Southeastern United States (U.S.) that is centered in the city of Kannapolis, NC and encompasses Cabarrus County, NC.

Creation of the cohort was funded by a gift to Duke University from the David H. Murdock Institute for Business and Culture, with operational support from Duke's Clinical and Translational Science Award (CTSA) grant (UL1TR002553) and the Duke Clinical and Translational Science Institute (CTSI).

Consenting participants complete a baseline health questionnaire at enrollment, as well as a brief physical exam and collection of blood and urine. Consent includes permission to access to information from medical records, storage of collected samples in the biorepository, access to collected data and biospecimens for future approved research studies and contact regarding new research study opportunities.

Data have been organized into "storefronts" that summarize characteristics of a population of research interest as well as available data and samples for that population. The following sections summarize the sources of data in the MURDOCK Study database, as well as important descriptions and definitions to help understand the data presented in the "storefronts".

1 Participant self-reported data at baseline. The baseline questionnaire collects contact information, current residential street address, and primary physician; alternate contact information; date and place of birth; demographics; current or past diagnosis of 34 medical conditions; menopausal status in women; medications, vitamins and supplements; dietary and physical activity assessment; hours of sleep per night; tobacco and alcohol use; second-hand smoke exposure; and selected PROMIS® participant-reported outcomes domains. Socioeconomic data collected at baseline included marital status, highest level of education of participant and participant's mother and father, employment status, mother's and father's occupations, housing (type, how paid for, number of adults and children in the household) and total household income. In addition, a brief phy sical exam (vital signs, height, and waist circumference) was conducted at enrollment.

Medical conditions: "Do you have, or have you ever had, any of the following [medical conditions]?" (yes, no, don't know). Counts are unique participants reporting yes to specific condition. Medications: "Please list any pharmaceutical and/or natural medications (including vitamins) that you are currently taking." Data are captured in free-text format as written by the participant and coded using RxNorm. Summary metrics are based on everything reported. Top 5 reported medications are limited to reported prescriptions.

2 Biorepository samples. Blood was collected at baseline and processed into the following specific samples: whole blood in EDTA for DNA extraction, whole blood in PAXgene for RNA extraction, plasma, serum and buffy coat in cry ovials. Urine was collected and aliquoted in cry ovials. Serial sample collection was not done systematically for MURDOCK enrollees; however, some nested sub cohorts and other studies enrolling MURDOCK registry participants include sample collection at follow up time points. All samples are stored at -80°C in a central biorepository current managed by Fisher BioServices, a division of Thermo Fisher Scientific, under a contractual agreement with Duke University.

Samples in inventory: Data are summarized by sample type as well as specific container and size. Participant counts are unique individuals with one ore more aliquots. Aliquot counts are all unique samples for a given type and container, size. Freezers is a calculation of approximate storage requirements based on sample type/size, box size, and number of boxes that can be stored per freezer.

3 Participant self-reported changes in health via annual follow up. Participants are asked to complete a follow-up form once a year around the time of their original enrollment date. Participants may update contact information, primary care physician/practice and alternate contact. PROMIS domains are repeated at each annual time point in order to capture changes in participant-reported outcomes over time. The form collects new incidence/diagnosis of the same 34 medical conditions surveyed at baseline. Hospitalizations during the past year are collected along with reason, as well as specific medical procedures. Participants may update their medication list to reflect current medications, vitamins and supplements being taken at the time of follow up form completion.

Vital status: Death reported by family member or alternate contact is confirmed by obituary as the primary source. Cause of death is not captured. Follow-up metrics: Follow-up is defined as complete if participant fills out the survey online or by mail or phone. Completeness is measured as surveys completed relative to years eligible to complete follow-up. Medical conditions: "Please indicate if you have received a new diagnosis of any of the following medical conditions in the past year (yes, no, don't know)". Counts and percentages are unique participants reporting yes to specific condition in follow-up for participants that did NOT report yes at baseline. Procedures: "Please indicate if you have any of the following medical procedures in the past year". Counts are unique participants reporting the specified procedure one or more times during follow up. Hospitalizations: Participants are asked to report if they have been hospitalized within the last year, for each hospitalization they are asked to list reason(s) for hospitalization, admission date and hospital name. Reasons for hospitalization are captured as free-text responses as written by participants. Responses are coded, when possible, in order to list the most frequently reported reasons for hospitalization. Medications: (see note above for medications reported at baseline). The denominator for data based on last follow-up are participants with at least one follow-up survey complete.

4 Electronic health record (EHR) data from regional healthcare providers. Duke has partnered with regional healthcare providers to integrate data from EHR systems for consented MURDOCK Study participants. Participants are identified in EHR systems with robust matching algorithms using common identifiers from the MURDOCK and EHR databases. Data are transferred under a data use agreement (DUA) with the specific provider organization which specifies the scope of data and frequency of transfers. Data availability vary by participant and depend on whether or not a participant has had one or more encounters with the healthcare provider system during the time period included in the dataset.

Available EHR datasets: Data are summarized by healthcare provider organizations. Counts are unique participants with one or more ICD codes in the EHR dataset. Available EHR domains: Data area summarized by domain in the EHR dataset. Counts are unique participants with one of more records (rows of data) for the specified domain. Insights from available EHR data: Specific EHR data related to the population of research interest is presented with granularity when possible.

5 Additional data collection from studies with MURDOCK participants. MURDOCK Study participants may be recruited to enroll in additional research study opportunities by Duke researchers or other collaborators. Data sharing is a condition of collaboration with with the MURDOCK Study; therefore, data collected from MURDOCK Study participants and/or generated from biospecimens as part of additional research studies is returned for integration with all other MURDOCK registry data.

"Storefronts" for nested sub-cohorts summarize surveys, assessments and/or other data collected specifically as part of enrollment and participation in the study. **Samples in inventory**: Samples are summarized if collected (see note above for samples collected at baseline). **Participation in other studies**: Counts are participants from the population of research interest enrolled in the specified study listed. *Brief descriptions of relevant studies are listed along with a summary of study procedures and/or data collected.* 



Melanoma

Breast cancer

Liver disease

Crohn's disease/ulcerative colitis

## MURDOCK Study participants with rheumatoid arthritis, N=1,790

## Participant self-reported characteristics at MURDOCK Study enrollment (baseline, February 2009 – February 2018)

Demographics at baseline		Education at	baseline					
Age				Less than high school graduate				
Median (25th, 75th)	60 (50, 68)	High school graduate, equivalent				268 (15%) 481 (27%)		
Min, Max	<18, 90+	Some college or associates degree				666 (37%)		
Sex		Bachelor's degree				236 (13%)		
Female	1,195 (67%)	Master's or higher professional degree				138 (8%)		
Male	Income at baseline							
Race	Under \$10,000				201 (11%)			
American Indian & Alaska Native	7 (<1%)	\$10,000-29,999				446 (25%)		
Asian	\$30,000-49,999				319 (18%)			
Black or African American	6 (<1%) 343 (19%)	\$50,000-69,999				223 (12%)		
Native Haw aiian & Other Pacific Islander	1 (<1%)	\$70,000-89,999				150 (8%)		
White/Caucasian	1,247 (70%)	\$90,000 or more		196 (11%)				
Other	131 (7%)	Don't know, no response			255 (15%)			
Multiple	40 (2%)	Body mass index (BMI) at baseline				200 (1070)		
Don't know /Not sure/Not answ ered	15 (<1%)					10 (10/.)		
Ethnicity	,	,	<b>•</b> /			18 (1%)		
Hispanic or Latino	178 (10%)	18.5 - 24.9 (normal w eight) 25 - 29.9 (overweight)				326 (18%)		
Non-Hispanic or Latino	1,571 (88%)	30+ (obese)				591 (33%) 843 (47%)		
Don't know /Not sure/Not answ ered	41 (2%)					043 (47 70)		
Sm oking history at baseline	Exercise at baseline				074 (400()			
Smoked	893 (50%)	Little to no physical activity				874 (49%)		
Never smoked	883 (49%)	Weekend light exercise  Moderate activity 3x per w eek				298 (17%)		
Don't know, no response	Heavy activity 3x per w eek				419 (23%) 99 (6%)			
Current or prior medical conditions reported					83 (5%)			
27 of 34 solicited medical conditions, listed by a	Medications, vitamins, supplements at baseline							
High blood pressure	1,004 (56%)		75th) reported			7 (4, 11)		
High cholesterol	957 (53%)	10+ reported, n (%)				597 (33%)		
Rheumatoid arthritis	882 (49%)	Top 5 reported medications				337 (3370)		
Obesity	634 (35%)	Lisinopril				262 (200/)		
Depression	606 (34%)	•				363 (20%)		
Osteoarthritis	2.0 (2.73)		Hydrochlorothiazide			296 (16%)		
Diabetes	437 (24%)	Omeprazole				291 (16%)		
Asthma	311 (17%)	Levothyroxine				259 (14%)		
Thyroid disease	280 (16%)	Simvastatin				252 (14%)		
Skin cancer, not melanoma	218 (12%)	-	rently in inventory					
Osteoporosis/Osteopenia	208 (12%)	Sam ple	Container, Size	Participar	ntsAliquot	s Freezers		
Heart attack or angina	175 (10%)	Plasma	Cryovial, 0.5 mL	1,642	20,085	0.354		
Other autoimmune disease	165 (9%)	Serum	Cryovial, 0.5 mL	1,665	14,609	0.258		
Gout	164 (9%)		Cryovial, 5.0 mL	1,484	1,484	0.052		
Coronary artery disease	163 (9%)	Whole blood	PAXgene RNA	1,580	3,573	0.208		
Emphysema or "COPD"	163 (9%)		Vacutainer, 2.0 mL	824	1,288	0.038		
Atrial fibrillation	126 (7%)	Buffy coat	Cryovial, 2.0 mL	0	0	0.000		
Other mental illness	115 (6%)	Urine	Cryovial, 0.5 mL	6	6	0.000		
Stroke	111 (6%)		Cryovial, 10.0 mL	1,566	1,566	0.124		
Congestive heart failure	76 (4%)	Total			42,611	1.034		
Other type of cancer	76 (4%)							
Kidney disease	75 (4%) 71 (4%)							
Multiple sclerosis								

59 (3%)

52 (3%)

51 (3%) 48 (3%)



## MURDOCK Study participants with Rheumatoid Arthritis, N=1,790

Participant status and data from MURDOCK Study follow-up surveys and electronic health records
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Participa	nt vital status	as arra date	THOM WORL	DOON Oldu	New medical condition diagnoses reported in	n follow-up	)	
Alive			1,4	418 (79%)	15 of 34 solicited medical conditions, listed by d	- J	, ,	
Deceased	I			372 (21%)	Rheumatoid arthritis		908 (99%)	
Current A	\ae			Current	Osteoarthritis	478 / 1,242 (3		
Median (2			6	69 (60, 78)	High cholesterol	268 /	833 (32%)	
Min, Max	0,70,			27, 90+	High blood pressure	249 /	786 (32%)	
			21, 30+	Osteoporosis/Osteopenia	248 / 1,	,582 (16%)		
Follow-up metrics, study participation  Median (25th, 75th) months since enrollment 147 (125,25, 159)				F 0F 4F0)	Depression	213 / 1,184 (18%)		
				5.25, 159)	Obesity	203 / 1,156 (18%)		
,	5th, 75th) years since enroll		1	12 (10, 13)	Other autoimmune disease	172 / 1,625 (11%)		
,	5th, 75th) yearly follow -ups			7 (3, 10)	Diabetes	170 / 1,	,353 (13%)	
	empleteness of follow -up, n	` '	11,245/16,6	` '	Emphysema or "COPD"	166 / 1,	,627 (10%)	
	ne (1) follow -up survey cor	nplete, n (%)		644 (92%)	Skin cancer, not melanoma		,572 (11%)	
	npletion (n, %)			514 (29%)	Thyroid disease	156 / 1,510 (10%)		
Last comp	leted follow-up≤18 month	IS	8	335 (47%)	Asthma	144 / 1,479 (10%)		
Enrolled in	one or more other studies	3	3	316 (46%)	Kidney disease	143 / 1,715 (8%)		
Available	EHR datasets by source	(any ICD c	ode)		Gout	138 / 1,626 (8%)		
Any sourc	e			890 (50%)		130 /	1,020 (076)	
Novant He	alth		6	623 (35%)	Procedures reported in follow up			
Cabarrus I	Health Alliance			314 (17%)	CT or MRI scan	1,	,278 (71%)	
Cabarrus I	Row an Community Health	Centers		123 (7%)	Joint x-ray	1,	,175 (66%)	
	Health Center			21 (1%)	Chest x-ray	1,	,124 (63%)	
	/ Free Clinic			30 (2%)	Heart/cardiac stress test		667 (37%)	
,				0	Joint replacement		385 (22%)	
Atrium (Carolinas Healthcare)			· ·	Heart/cardiac catheterization		229 (13%)		
Available EHR data domains			200 (500/)	Heart/cardiac angioplasty or stent 165				
Diagnoses 890 (5		` ′			79 (4%)			
Labs 725 (41%)			, ,	Hospitalizations reported in follow up				
Vitals				595 (33%)	Participants reporting 1 or more hospitalizations		936 (52%)	
Medication	1S			704 (39%)	Unique hospitalizations reported	1,602		
Allergies		352 (20%)		Median (25th, 75th) hospitalizations reported				
lmmunizat	ions		280 (16%)		Coded reasons for self-reported hospitalization	2 (1, 3)		
Problems				510 (28%)	listed in descending frequency	Events	Participants	
Procedures			399 (22%)		Uncoded	1,208	618	
Hospitalizations			3	329 (18%)	Surgery		170	
_	rom available EHR data				Knee replacement	233 171	124	
_	e: June 1993 (first encount			ounter)	Pneumonia	84	65	
	f days between first and las	st encounte	er: 1868.5 (196, 3263.5)		Chest pain			
Median (2 Min, Max	o, 7 o)		1000.5 (13	0, 10552		77	64	
·	ecodes, mapped from di	agnosi s co	des	0, 10002	Fracture	72	59	
Phecode	Description	Group		n, ppts	Body mass index (BMI) at most recent comp	leted follow up		
401.1	Essential hypertension	circulator	y system	251	<18.5 (underw eight)	34 (2%)		
272.1	Hyperlipidemia	endocrine	e/metabolic	219	18.5 - 24.9 (normal w eight)	361 (22%)		
250.2	Type 2 diabetes		e/metabolic	117	25 - 29.9 (overweight)	537 (33%)		
530.11	GERD	digestive	, , , , ,	108	30+		708 (43%)	
261.4	Vitamin D deficiency		e/metabolic	90	Medications, vitamins, supplements at most recent for		ow up	
278.1	Obesity	endocrine	e/metabolic	82	Median (25th, 75th) reported		7 (4, 12)	
Select laboratory tests Test Labs Pa			Lahs Pa	articinants			533 (30%)	
Comprehensive metabolic panel			3,284	421	Top 5 reported medications		000 (0070)	
CBC and differential		2,692	381			20E (470/)		
Basic metabolic panel		1,958	316	Atorvastatin		305 (17%)		
Hemoglobi			1,791	311	Lisinopril	296 (17%)		
TSH		1,232	306	Omeprazole	284 (16%)			
Lipid panel		1,394	285	Amlodipine	253 (14%)			
CBC			1,704	264	Levothyroxine		250 (14%)	