

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.*



Kidney disease

Implantable cardiac defibrillator

MURDOCK Study participants with breast cancer, N=593

Participant self-reported charact	eristics at MURDOCK Stu	udy enrollmen	t (baseline, Februa	ry 2009– Fel	oruary 20	18)	
Dem ographics at bas eline		Education at	baseline				
Age	Baseline	Less than hig	h school graduate			28 (5%)	
Median (25th, 75th)	edian (25th, 75th) 63 (53, 70)			High school graduate, equivalent			
Min, Max	Max 21, 90+			Some college or associates degree			
Sex	Bachelor's degree				126 (21%)		
Female	Master's or higher professional degree				81 (14%)		
Male	17 (3%)	Income at baseline					
Race		Under \$10,000			28 (5%)		
American Indian & Alaska Native	1 (<1%)	\$10,000-29,999			114 (19%		
Asian	1 (<1%)			\$30,000-49,999			
Black or African American	71 (12%)	\$50,000-69,999			95 (16%) 91 (15%)		
Native Haw aiian & Other Pacific Islander	1 (<1%)	\$70,000-89,999			64 (11%)		
White/Caucasian	487 (82%)	\$90,000 or more			126 (21%)		
Other	15 (3%)	Don't know, no response			75 (13%)		
Multiple	13 (2%)	Body mass index (BMI) at baseline					
Don't know /Not sure/Not answ ered	4 (<1%)	<18.5 (underw eight)				5 (1%)	
Ethnicity		18.5 - 24.9 (normal w eight)			181 (31%)		
Hispanic or Latino	22 (4%)	25 - 29.9 (overweight)			197 (34%)		
Non-Hispanic or Latino	564 (95%)	30+ (obese)				205 (35%)	
Don't know /Not sure/Not answ ered	7 (1%)	Exercise at I	paseline			(
Sm oking history at baseline			ysical activity			247 (42%)	
Smoked	Weekend light exercise			82 (14%)			
Never smoked	Moderate activity 3x per w eek			190 (32%)			
Never smoked 349 (59%) Don't know, no response 8 (1%)		Heavy activity 3x per w eek		43 (7%)			
Current or prior medical conditions reported at baseline 26 of 34 solicited medical conditions, listed by descending frequency		Heavy activity 5x per w eek 26 (4%)					
Breast cancer	316 (53%)	Medications	s, vitamins, supplen	nents at bas	eline		
High blood pressure	281 (47%)	Median (25th, 75th) reported			7 (4, 11)		
High cholesterol	275 (46%)	10+ reported, n (%)			190 (32%)		
Obesity	170 (29%)	Top 5 reported medications					
Osteoarthritis	159 (27%)	Levothyroxine 111 (1				111 (19%)	
Osteoporosis/Osteopenia	159 (27%)	Cholecalciferol				106 (18%)	
Depression	146 (25%)	Hydrochlorothiazide				100 (17%)	
Thyroid disease	128 (22%)	Lisinopril				85 (14%)	
Skin cancer, not melanoma	124 (21%)	Simvastatin				77 (13%)	
Diabetes	106 (18%)		rrently in inventory	(collected a	t baseline		
Asthma	68 (11%)	Sample	Container, Size	1		s Freezers	
Rheumatoid arthritis	47 (8%)	Plasma	Cryovial, 0.5 mL	543	6,515	0.115	
Coronary artery disease	35 (6%)	Serum	Cryovial, 0.5 mL				
Heart attack or angina	35 (6%)	20. 0.11	Cryovial, 5.0 mL	555 484	4,691 484	0.083 0.017	
Multiple sclerosis	35 (6%)	Whole blood	PAXgene RNA	529	1,130	0.017	
Other autoimmune disease	34 (6%)		Vacutainer, 2.0 mL		341	0.000	
Atrial fibrillation	30 (5%)	Buffy coat	Cryovial, 2.0 mL	0	0	0.010	
Other type of cancer	30 (5%)	Urine	Cryovial, 10.0 mL	526	526	0.00	
Emphysema or "COPD"	25 (4%)	Total	,, <u>.</u>	320	13,687	0.042	
Melanoma	24 (4%)				. 2,00.		
Congestive heart failure	22 (4%)						
Stroke	22 (4%)						
Gout	18 (3%)						
Other mental illness	17 (3%)						
	45 (20/)						

15 (3%)

15 (3%)



MURDOCK Study participants with breast cancer, N=593

Participant status and data from MURDO	CK Study follow-u	up surveys and electronic hea	Ith records
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	Participant state	us and data	a from MURI	OOCK Stud	y follow-up surveys and electronic health reco			
Participa Alive	nt vital status		2	479 (81%)	New medical condition diagnoses reported in follow-up 15 of 34 solicited medical conditions, listed by descending frequency			
Deceased	1			114 (19%)	Breast cancer	266	/ 277 (96%)	
				Current	Osteoporosis/Osteopenia	101 / 434 (23%)		
Current A			7		Osteoarthritis	99 / 434 (23%)		
Median (2	25 ^{tn} , 75 ^{tn})		/	3 (64, 80)	High cholesterol	91 / 318 (29%)		
Min, Max				34, 90+	Skin cancer, not melanoma		/ 469 (14%)	
	pmetrics, study participa				High blood pressure		/ 312 (21%)	
,	25th, 75th) months since enro		150 ((127, 163)	Rheumatoid arthritis	62 / 546 (11%)		
Median (2	25th, 75th) years since enroll	lment	1	2 (10, 13)	Thyroid disease		/ 465 (12%)	
Median (2	25th, 75th) yearly follow -ups	complete		8 (5, 11)	Atrial fibrillation		3 / 563 (9%)	
Overall co	ompleteness of follow -up, r	n/N (%)	4,394 / 5,6	644 (78%)	Obesity		/ 423 (11%)	
At least or	ne (1) follow -up survey cor	mplete, n (%)	5	559 (94%)	Diabetes		5 / 487 (9%)	
100% con	npletion (n, %)		2	242 (42%)	Depression			
Last comp	oleted follow-up≤18 month	ns	3	319 (54%)			/ 447 (10%)	
Enrolled in	n one or more other studies	S	3	311 (52%)	Other type of cancer		0 / 563 (7%)	
Available	EHR datasets by source	(any ICD c	ode)		Other autoimmune disease		5 / 559 (6%)	
Any source	•	(uny lob o		288 (49%)	Coronary artery disease	35	5 / 558 (6%)	
Novant He				205 (35%)	Procedures reported in follow up			
Cabarrus Health Alliance				102 (17%)	CT or MRI scan	461 (78%)		
Cabarrus	Row an Community Health	Centers		20 (3%)	Chest x-ray		371 (63%)	
	Bethesda Health Center			1 (<1%)	Joint x-ray		348 (59%)	
	y Free Clinic				Heart/cording stress test		196 (33%)	
	unity Free Clinic 2 (<1%) (Carolinas Healthcare)		Joint replacement	94 (16%)				
,	<u> </u>				Heart/cardiac catheterization	52		
	EHR data domains			000 (400/)	Heart/cardiac angioplasty or stent 3			
Labs	agnoses 288 (49		233 (39%)	Coronary artery bypass surgery		9 (2%)		
Vitals				209 (35%)	Hospitalizations reported in follow up			
Medication	no			224 (38%)	Participants reporting 1 or more hospitalizations		333 (56%)	
	115			` '	Unique hospitalizations reported	591		
Allergies	.ia.a			144 (24%)	Madian (Ofth 75th) beautiful ations reported		2 (1, 3)	
Immunizat			101 (17%)	Coded reasons for self-reported hospitalization				
Problems		178 (30%)		listed in descending frequency	Events Participants			
Procedures		145 (24%)		Uncoded	456	179		
Hospitalizations		1	14 (19%)	Surgery	142	109		
_	from available EHR data	\ .	00.41		Cancer	60	52	
_	je: July 1993 (first encounte			ounter)	Pneumonia	28	22	
Median (2	of days between first and las	st encounte	2,311 (41)	8 3461 5)	Chest pain	25	17	
Min, Max	.5, 75)		2,011 (41)	0, 8886	AFIB	22	16	
	necodes, mapped from di	agnosi s co	des	.,			-	
Phecode -	Description	Group		n, ppts	Body mass index (BMI) at most recent comp	letedfollo		
174.1	Breast cancer [female]	Neoplasm		77	<18.5 (underw eight)	19 (3%)		
401.1	Essential hypertension	Circulator		73	18.5 - 24.9 (normal w eight)	190 (34%)		
272.1	Hyperlipidemia		e/metabolic	73	25 - 29.9 (overweight)	173 (31%)		
261.4 530.11	Vitamin D deficiency GERD	endocrine Digestive	e/metabolic	42 30	30+	177 (32%)		
244.4	Hypothyroidism NOS		e/metabolic	29	Medications, vitamins, supplements at most	recentfollow up		
	boratory tests	0.100010	,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,		Median (25th, 75th) reported		7 (4, 11)	
Test			Labs Pa	articipants	10+ reported, n (%)		168 (28%)	
	ensive metabolic panel		1,097	132	Top 5 reported medications		, ,	
	differential		906	125	5 Levothyrovine 12		124 (21%)	
TSH	.1		530	106	Lisinopril	89 (15%)		
Lipid pane			515 600	105	Atorvastatin	87 (15%)		
	asic metabolic panel 609 emoglobin A1C 456		456	100 94		75 (13%)		
CBC	, \ 10		415	94	Losartan			
OBO			410	91	Amlodipine		70 (12%)	