MURDOCK STUDY

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 physical exam (vital signs, height, weight, 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 cryovials. Urine was collected and aliquoted in cryovials. 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.*

## MURDOCK Study participants with kidney disease, N=823

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

| Demographics at baseline | |
|---|---|
| **Age** | **Baseline** |
| Median (25th, 75th) | 63 (51, 72) |
| Min, Max | 19, 90+ |
| **Sex** | |
| Female | 528 (64%) |
| Male | 295 (36%) |
| **Race** | |
| American Indian & Alaska Native | 3 (<1%) |
| Asian | 0 |
| Black or African American | 132 (16%) |
| Native Hawaiian & Other Pacific Islander | 0 |
| White/Caucasian | 575 (70%) |
| Other | 87 (11%) |
| Multiple | 12 (1%) |
| Don't know/Not sure/Not answered | 14 (2%) |
| **Ethnicity** | |
| Hispanic or Latino | 113 (14%) |
| Non-Hispanic or Latino | 696 (85%) |
| Don't know/Not sure/Not answered | 14 (2%) |
| **Smoking history at baseline** | |
| Smoked | 379 (46%) |
| Never smoked | 437 (53%) |
| Don't know, no response | 7 (1%) |

| Current or prior medical conditions reported at baseline<br>*26 of 34 solicited medical conditions, listed by descending frequency* | |
|---|---|
| High blood pressure | 554 (67%) |
| High cholesterol | 504 (61%) |
| Obesity | 337 (41%) |
| Kidney disease | 296 (36%) |
| Diabetes | 273 (33%) |
| Depression | 262 (32%) |
| Osteoarthritis | 227 (28%) |
| Thyroid disease | 178 (22%) |
| Asthma | 138 (17%) |
| Osteoporosis/Osteopenia | 135 (16%) |
| Skin cancer, not melanoma | 132 (16%) |
| Rheumatoid arthritis | 118 (14%) |
| Heart attack or angina | 118 (14%) |
| Coronary artery disease | 114 (14%) |
| Gout | 111 (13%) |
| Atrial fibrillation | 83 (10%) |
| Emphysema or "COPD" | 77 (9%) |
| Other autoimmune disease | 67 (8%) |
| Other type of cancer | 67 (8%) |
| Stroke | 65 (8%) |
| Congestive heart failure | 63 (8%) |
| Liver disease | 44 (5%) |
| Multiple sclerosis | 42 (5%) |
| Other mental illness | 41 (5%) |
| Melanoma | 41 (5%) |
| Implantable cardiac defibrillator | 29 (4%) |

| Education at baseline | |
|---|---|
| Less than high school graduate | 128 (16%) |
| High school graduate, equivalent | 207 (25%) |
| Some college or associates degree | 304 (37%) |
| Bachelor's degree | 122 (15%) |
| Master's or higher professional degree | 62 (8%) |
| **Income at baseline** | |
| Under $10,000 | 70 (9%) |
| $10,000-29,999 | 209 (25%) |
| $30,000-49,999 | 147 (18%) |
| $50,000-69,999 | 104 (13%) |
| $70,000-89,999 | 56 (7%) |
| $90,000 or more | 102 (12%) |
| Don't know, no response | 135 (16%) |
| **Body mass index (BMI) at baseline** | |
| <18.5 (underweight) | 6 (1%) |
| 18.5 - 24.9 (normal weight) | 150 (18%) |
| 25 - 29.9 (overweight) | 288 (35%) |
| 30+ (obese) | 373 (46%) |
| **Exercise at baseline** | |
| Little to no physical activity | 440 (53%) |
| Weekend light exercise | 117 (14%) |
| Moderate activity 3x per week | 176 (21%) |
| Heavy activity 3x per week | 41 (5%) |
| Heavy activity 5x per week | 41 (5%) |
| **Medications, vitamins, supplements at baseline** | |
| Median (25th, 75th) reported | 8 (4, 12) |
| 10+ reported, n (%) | 347 (42%) |
| **Top 5 reported medications** | |
| Lisinopril | 186 (23%) |
| Omeprazole | 152 (18%) |
| levothyroxine | 146 (18%) |
| Simvastatin | 139 (17%) |
| Hydrochlorothiazide | 138 (17%) |

**Samples in inventory, collected at baseline**

| Sample | Container, Size | Participants | Aliquots | Freezers |
|---|---|---|---|---|
| Plasma | Cryovial, 0.5 mL | 776 | 10,438 | 0.184 |
| | Cryovial, 4.0 mL | 0 | 0 | 0 |
| Serum | Cryovial, 0.5 mL | 776 | 6,754 | 0.119 |
| | Cryovial, 4.0 mL | 0 | 0 | 0 |
| | Cryovial, 5.0 mL | 685 | 685 | 0.024 |
| Whole blood | PAXgene RNA | 742 | 1,662 | 0.096 |
| | Vacutainer, 2.0 mL | 388 | 626 | 0.018 |
| | Vacutainer, 3.0 mL | 0 | 0 | 0 |
| | Vacutainer, 4.0 mL | 0 | 0 | 0 |
| Buffy coat | Cryovial, 2.0 mL | 520 | 520 | 0.009 |
| Urine | Cryovial, 4.0 mL | 0 | 0 | 0 |
| | Cryovial, 10.0 mL | 744 | 2,350 | 0.186 |
| Total | | | | 0.636 |

## MURDOCK Study participants with kidney disease, N=823

### Participant status and data from MURDOCK Study follow-up surveys and electronic health records

| **Participant vital status** | |
|---|---|
| Alive | 618 (75%) |
| Deceased | 205 (25%) |
| **Current Age** | |
| Median (25th, 75th) | 70 (59, 79) |
| Min, Max | 25, 90+ |
| **Follow-up metrics, study participation** | |
| Median (25th, 75th) months since enrollment | 126 (104, 142) |
| Median (25th, 75th) years since enrollment | 11 (9, 12) |
| Median (25th, 75th) yearly follow-ups complete | 6 (3, 9) |
| Overall completeness of follow-up, n/N (%) | 4,500 / 6,507 (69%) |
| At least one (1) follow-up survey complete, n (%) | 750 (91%) |
| 100% completion (n, %) | 277 (34%) |
| Last completed follow-up ≤ 18 months | 430 (52%) |
| Enrolled in one or more other studies | 379 (46%) |
| **Available EHR datasets by source (any ICD code)** | |
| Any source | 473 (57%) |
| Novant Health | 353 (43%) |
| Cabarrus Health Alliance | 141 (17%) |
| Cabarrus Rowan Community Health Centers | 57 (7%) |
| Bethesda Health Center | 15 (2%) |
| Community Free Clinic | 14 (2%) |
| Atrium (Carolinas Healthcare) | 0 |
| **Available EHR data domains** | |
| Diagnoses | 473 (57%) |
| Labs | 389 (47%) |
| Vitals | 330 (40%) |
| Medications | 400 (49%) |
| Allergies | 238 (29%) |
| Immunizations | 200 (24%) |
| Problems | 313 (38%) |
| Procedures | 237 (29%) |
| Hospitalizations | 217 (26%) |
| **Insights from available EHR data** | |
| Date range: Oct. 1993 (first encounter), Jan. 2021 (last encounter) | |
| *Number of days between first and last encounter:* | |
| Median (25th, 75th) | 2,072 (565, 2,995) |
| Min, Max | 0, 9,752 |

***Select phecodes, mapped from diagnosis codes***

| *Phecode* | *Description* | *Group* | *n, ppts* |
|---|---|---|---|
| 401.1 | Essential hypertension | circulatory system | 188 |
| 272.1 | Hyperlipidemia | endocrine/metabolic | 170 |
| 585.3 | Chronic renal failure | Genitourinary | 96 |
| 250.2 | Type 2 diabetes | endocrine/metabolic | 95 |
| 530.1 | Esophagitis, GERD | Digestive | 85 |
| 296.2 | Depression | mental disorders | 68 |

***Select laboratory tests***

| *Test* | *Labs* | *Participants* |
|---|---|---|
| Comprehensive metabolic panel | 2,397 | 271 |
| CBC and differential | 1,807 | 244 |
| Basic metabolic panel | 2,005 | 222 |
| TSH | 1,008 | 213 |
| Hemoglobin A1C | 1,147 | 211 |
| Lipid panel | 950 | 200 |
| CBC | 1,595 | 185 |

| **New medical condition diagnoses reported in follow-up** | |
|---|---|
| *15 of 34 solicited medical conditions, listed by descending frequency* | |
| Kidney disease | 389 / 527 (74%) |
| Osteoarthritis | 149 / 596 (25%) |
| Rheumatoid arthritis | 114 / 705 (16%) |
| High cholesterol | 102 / 319 (32%) |
| Osteoporosis/Osteopenia | 85 / 688 (12%) |
| Thyroid disease | 84 / 645 (13%) |
| Congestive heart failure | 81 / 760 (11%) |
| Depression | 80 / 561 (14%) |
| Skin cancer, not melanoma | 78 / 691 (11%) |
| High blood pressure | 77 / 269 (29%) |
| Emphysema or "COPD" | 74 / 746 (10%) |
| Diabetes | 73 / 550 (13%) |
| Atrial fibrillation | 70 / 740 (9%) |
| Gout | 69 / 712 (10%) |
| Coronary artery disease | 69 / 709 (10%) |
| **Procedures reported in follow up** | |
| CT or MRI scan | 580 (70%) |
| Chest x-ray | 495 (60%) |
| Joint x-ray | 441 (54%) |
| Heart/cardiac stress test | 309 (38%) |
| Joint replacement | 120 (15%) |
| Heart/cardiac catheterization | 117 (14%) |
| Heart/cardiac angioplasty or stent | 73 (9%) |
| Coronary artery bypass surgery | 33 (4%) |
| **Hospitalizations reported in follow up** | |
| Participants reporting 1 or more hospitalizations | 449 (55%) |
| Unique hospitalizations reported | 787 |
| Median (25th, 75th) hospitalizations reported | 2 (1, 4) |

| Coded reasons for self-reported hospitalization *listed in descending frequency* | Events | Participants |
|---|---|---|
| Uncoded | 683 | 313 |
| Surgery | 108 | 80 |
| Knee replacement | 43 | 34 |
| Stroke | 41 | 33 |
| Pneumonia | 43 | 32 |
| Kidney stone | 36 | 29 |

| **Body mass index (BMI) at most recent completed follow up** | |
|---|---|
| <18.5 (underweight) | 15 (2%) |
| 18.5 - 24.9 (normal weight) | 189 (25%) |
| 25 - 29.9 (overweight) | 246 (33%) |
| 30+ | 296 (40%) |
| **Medications, vitamins, supplements at most recent follow up** | |
| Median (25th, 75th) reported | 8 (4, 12) |
| 10+ reported, n (%) | 279 (34%) |
| **Top 5 reported medications** | |
| Levothyroxine | 165 (20%) |
| Atorvastatin | 146 (18%) |
| Metoprolol | 138 (17%) |
| Amlodipine | 134 (16%) |
| Omeprazole | 123 (15%) |