

# Caregiving and Families

Julia Rivera Drew

Sarah Flood

Prepared for the Summer 2022 NDIRA Pre-Conference Workshop

July 19, 2022

## MEPS Household Component

- Collected annually by Agency for Healthcare Research and Quality (AHRQ) since 1996
- Only nationally-representative source for information on US medical expenditures
- Short panel covering two calendar years
- Representative of civilian non-institutionalized US population

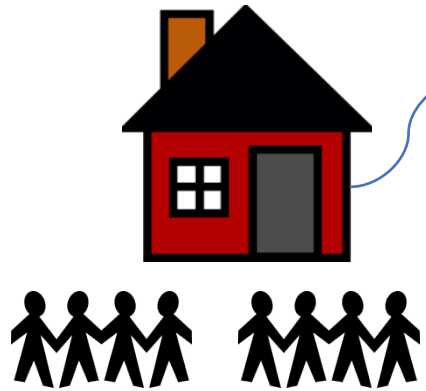
## Topics covered by MEPS

- Health care utilization: Types and dates of medical care use throughout the two-year panel, reason for visit, types of services used, type of provider seen
- Health care expenditures: Amounts for care, amounts paid by specific payers (e.g., self/family, Medicare, private insurance)
- Medical conditions

# DATA-INTENSIVE RESEARCH CONFERENCE

Pre-conference workshop  
presented by **IPUMS** and **NDiRA**

## (1) Household Component



**MEPS public use data**

## (2) Medical Provider Component



## (3) Pharmacy Component



## MEPS data on formal and informal caregiving

- Family respondents provide information on home health events for family members
- Formal (paid) care from an agency or independent provider
  - Informal (unpaid) care from someone outside the household (friend/neighbor, relative, volunteer)
- For families that give permission, paid home health providers are contacted for expenditure information

# DATA-INTENSIVE RESEARCH CONFERENCE

Pre-conference workshop  
presented by **IPUMS** and **NDiRA**

## Structure of MEPS Person Data

mepsid	agelast	sex	marstat	famsize	race	hispth	usborn	educ	cancerev
2291700101	85	Male	Widowed	1	White	Not Hispanic	Yes, born in U.S.	High school graduate	Yes

# DATA-INTENSIVE RESEARCH CONFERENCE

Pre-conference workshop  
presented by **IPUMS** and **NDiRA**

## Structure of MEPS Medical Condition Data

mepsid	condid	ICD10 Code	Number of Home Health Events
2291700101	0003	Other and unspecified osteoarthritis	0
2291700101	0006	Other disorders of external ear	0
2291700101	0007	Heart failure	13
2291700101	0008	Pneumonia, unspecified organism	0
2291700101	0009	Pneumonia, unspecified organism	0
2291700101	0010	Cannot be computed	6
2291700101	0011	Pain, unspecified	0
2291700101	0012	Other functional intestinal disorders	0

# DATA-INTENSIVE RESEARCH CONFERENCE

Pre-conference workshop  
presented by **IPUMS** and **NDiRA**

## Structure of MEPS Home Health Data

mepsid	evntid	# days in month received care	Month	Year	Type of home health care provider	Care provider was a home health aide	Self/Agency
2291700101	003001	8	1	2018	Other (paid)	No	Agency
2291700101	003201	1	1	2018	Other (paid)	No	Agency
2291700101	003501	20	1	2018	Relative	n/a	n/a
2291700101	003101	8	2	2018	Other (paid)	No	Agency
2291700101	003301	1	2	2018	Other (paid)	No	Agency
2291700101	003601	20	2	2018	Relative	n/a	n/a
2291700101	003701	20	3	2018	Relative	n/a	n/a
2291700101	003801	28	4	2018	Relative	n/a	n/a
2291700101	103901	28	5	2018	Relative	n/a	n/a
2291700101	104701	2	5	2018	Other (paid)	n/a	Self



## Using MEPS to Study Caregiving

1. Characteristics of formal or informal (nonresidential) home health care
  - Who provides it? What kinds of care? How often? How much does it cost (formal care)? Who pays for it?
2. Link in-home care received to information on care recipients
3. Identify in-home care received for specific medical conditions
  - Characteristics of care
  - Link condition-specific care to information on care recipients
4. Information available on all co-residential family members, but no measures of care provided by them

## Challenges to using MEPS data to study caregiving

- Large number of files with different units of analysis released each year mean data management can be daunting

# DATA-INTENSIVE RESEARCH CONFERENCE

Pre-conference workshop  
presented by **IPUMS** and **NDiRA**

Select by year and/or data file type

Year:

Data file types to include in search (check all that apply). Click information icon ⓘ for file details. Click link for full list of file types in category.

- Search all data files ⓘ
- Household Component Full-Year files** ⓘ  
Expenditure and utilization data for the calendar year from several rounds of data collection.
  - Full-Year Consolidated Data files** ←
  - Full-Year Population Characteristics files
  - Full-Year Medical Organizations Survey files
  - Medical Conditions files** ←
  - Risk Adjustment Scores files
  - Employment Variables file
  - Jobs files
  - Food Security file
  - Person Round Plan files
  - Longitudinal Data files
  - Preventive Care Self-Administered Questionnaire file (2014)
  - Supplemental Variables files (1996-2000)
  - Health Insurance Plan Abstraction file (1996)
  - Long Term Care file (1998)
- Household Component Event files** ⓘ  
Data for the calendar year on unique household-reported medical events.
  - Prescribed Medicines files
  - Dental Visits files**
  - Other Medical Expenses files
  - Hospital Inpatient Stays files
  - Emergency Room Visits files
  - Outpatient Visits files
  - Office-Based Medical Provider Visits files
  - Home Health files** ←
- Appendix to MEPS Event files** ⓘ  
Including the condition-event linkage file (CLNK) and PMED-event linkage file (RXLK). ←

Information about demographics, mental health, health insurance

Information about medically-treated medical conditions

Information about home health events

Linking keys to combine information on home health events with medical conditions

## Challenges to using MEPS data to study caregiving

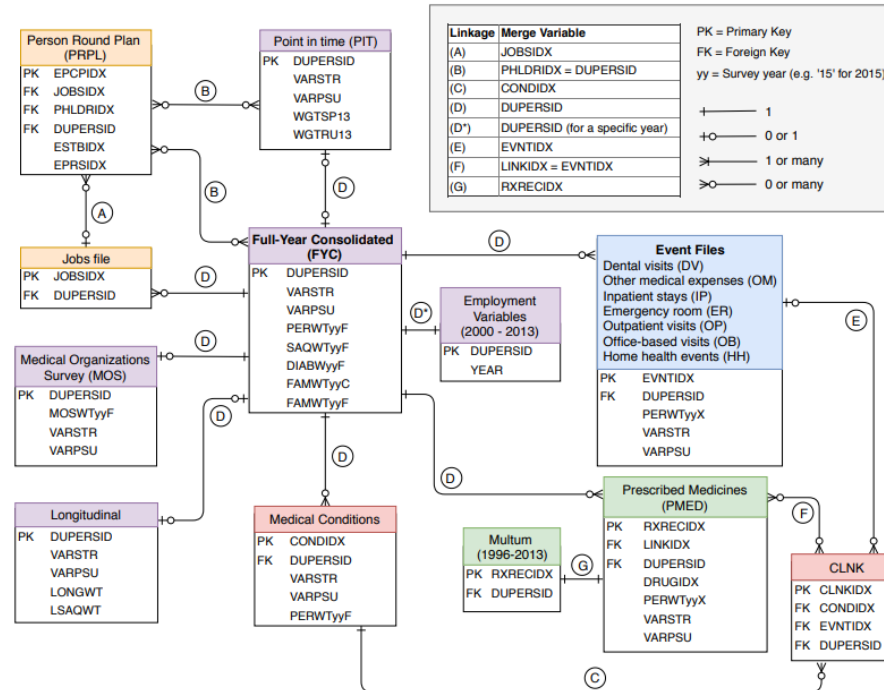
- Large number of files with different units of analysis released each year mean data management can be daunting
- Linking in the MEPS is especially complex

# DATA-INTENSIVE RESEARCH CONFERENCE

Pre-conference workshop  
presented by **IPUMS** and **NDiRA**

## MEPS Public Use Files (PUFs)

Entity Relationship Diagram (ERD) with survey and linkage variables



Type	Variable	Label
ID	CLNKIDX	CLNK ID: CONDIDX + EVNTIDX
	CONDIDX	CONDITION ID
	DRUGIDX	DRUG ID (DUPERSID + COUNTER)
	DUPERSID	PERSON ID
	EPCPIDX	UNIQUE RECORD ID (EPRSDX + DUPERSID)
	EPRSDX	ESTBIDX + POLICYHOLDER ID + ROUND NUMBER
	ESTBIDX	ESTABLISHMENT ID
	EVNTIDX	EVENT ID
	JOBSIDX	JOB ID NUMBER
	LINKIDX	ID FOR LINKAGE TO COND/OTHER EVENT FILES
	PHLDRIDX	POLICYHOLDER'S DUPERSID
	RXRECIDX	UNIQUE RX/PREScribed MEDICINE IDENTIFIER

Type	Variable	Label
Survey	VARPSU	VARIANCE ESTIMATION PSU
	VARSTR	VARIANCE ESTIMATION STRATUM
Weight	DIABWyyF	FINAL DIABETES CARE SUPPLEMENT WEIGHT
	FAMWyyC	POVERTY ADJUSTED FAMILY WEIGHT (CPS FAMILY)
	FAMWyyF	FINAL FAMILY WEIGHT
	LONGWT	LONGITUDINAL WEIGHT
	LSAQWT	LONGITUDINAL SAQ WEIGHT
	MOSWyyF	MOS FILE FINAL PERSON WEIGHT
	PERWyyF	FINAL PERSON WEIGHT
	SAQWyyF	FINAL SAQ PERSON WEIGHT
	WGTRU13	FAMILY WEIGHT, ROUND 1/3
	WGTSP13	PERSON WEIGHT, ROUND 1/3

This graphic contains information for the most common linkages among the most frequently used datasets. For complete descriptions of all MEPS Public



## Challenges to using MEPS data to study caregiving

- Large number of files with different units of analysis released each year mean data management can be daunting
- Linking in the MEPS is especially complex
- Changes over time in variable names, variable availability, and in how data are collected



## Illustrations: Using MEPS to Study Caregiving

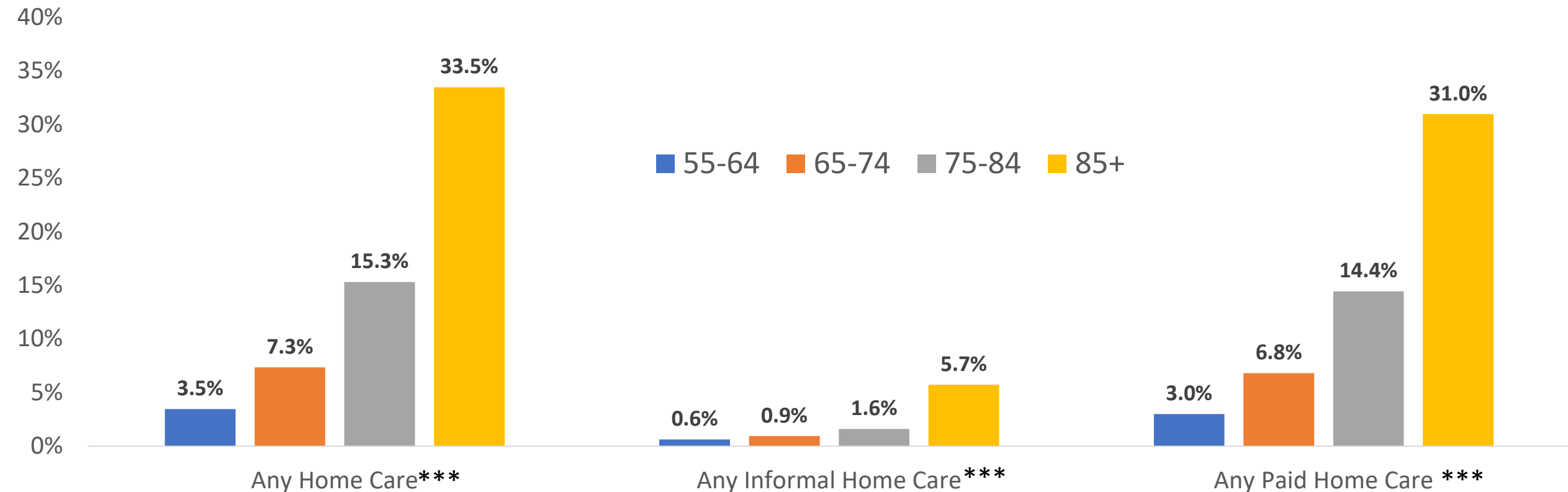
- [Exploring the home healthcare workforce in Alzheimer's disease and related dementias: Utilization and cost outcomes in US community dwelling older adults](#)
- [Future Demand for Long-Term Care Workers Will Be Influenced by Demographic and Utilization Changes](#)



# DATA-INTENSIVE RESEARCH CONFERENCE

Pre-conference workshop  
presented by **IPUMS** and **NDiRA**

## Receipt of home care by care provider type and age, community-dwelling adults 55+



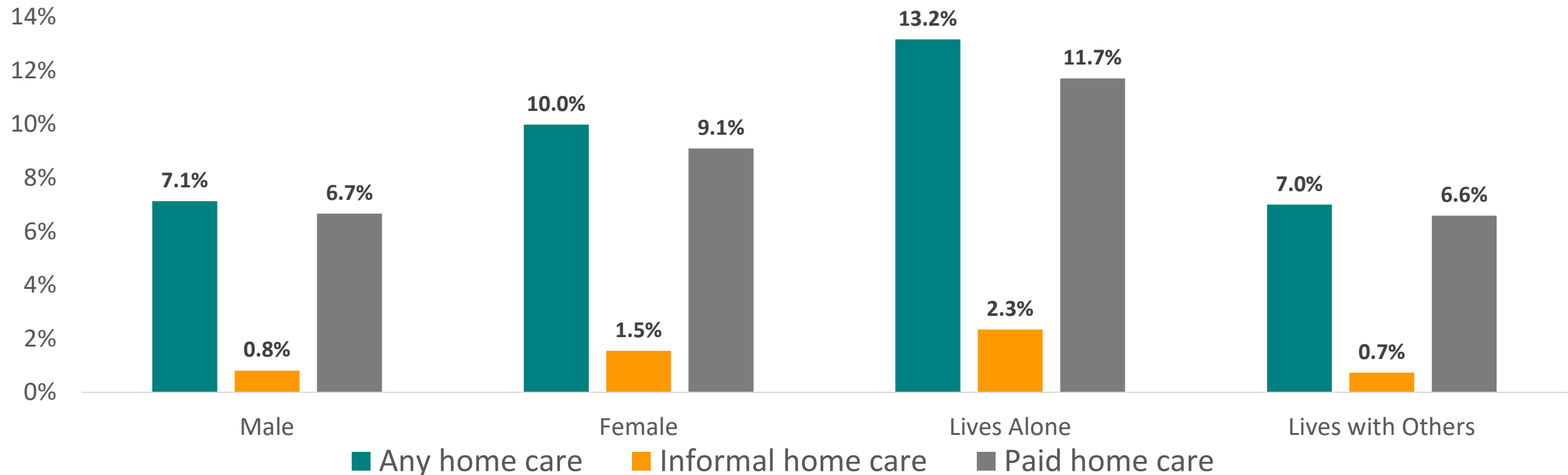
Source: Own analyses of 2016-19 MEPS-HC data

\* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$

# DATA-INTENSIVE RESEARCH CONFERENCE

Pre-conference workshop  
presented by **IPUMS** and **NDiRA**

## Receipt of home care by provider type, sex, and living alone for community-dwelling adults 55+



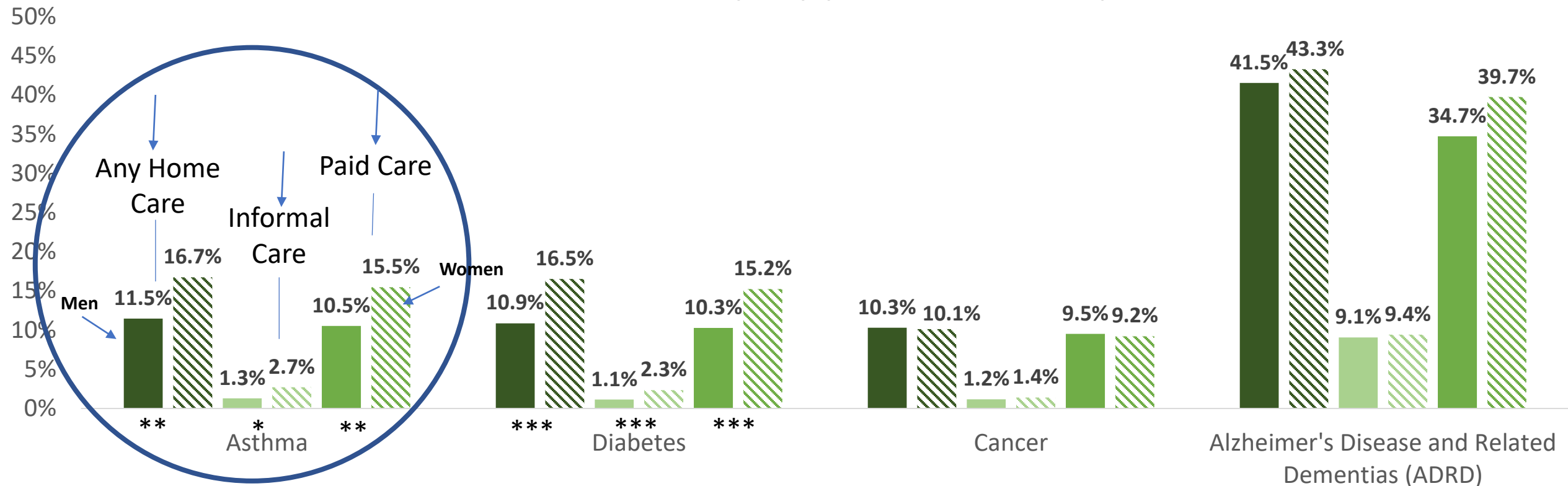
Source: Own analyses of 2016-19 MEPS-HC data, estimates are age-standardized to 2019 Census population estimates

All differences by sex and living arrangements statistically significant at  $p < 0.001$

# DATA-INTENSIVE RESEARCH CONFERENCE

Pre-conference workshop  
presented by **IPUMS** and **NDiRA**

## Receipt of home care for community-dwelling adults 55+ with selected conditions, by type of care provider and sex



Source: Own analyses of 2016-19 MEPS-HC data, estimates are age-standardized to 2019 Census population estimates

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001; (solid: men, striped: women)

## Additional Opportunities

- Identify plausible co-residential caregivers and study their mental health, physical health, and employment outcomes
  - Detailed information on all household members
  - Can study association with non-coresidential informal and formal home care on plausible caregiver outcomes

## Coming Features: MEPS variable builder

- Needing to work directly with data on the child records can act as a barrier to using the MEPS data in analysis
- Planned activity to develop a VARIABLE BUILDER that would allow users to
  - Define summary variables based on child record types through an easy-to-use interface
  - Include any user-defined summary variables in your IPUMS extract as a person-level variable
- Examples:
  - a count of medical encounters for diabetes by type of provider
  - the sum of medical expenditures paid for by self/family for cancer across all medical encounters

# DATA-INTENSIVE RESEARCH CONFERENCE

Pre-conference workshop  
presented by **IPUMS** and **NDiRA**

## ATUS

- 2003-present survey & time diary data
- Persons ages 15 and older complete a 20-minute telephone CATI interview conducted by the U.S. Census Bureau for the Bureau of Labor Statistics
  - They provide information about all of the activities they engage in over a 24-hour period as well as where, when, and with whom they complete them
  - Information about primary and secondary activities related to childcare and eldercare
- Primary source for annual estimates of population time allocation
- Additional information collected from adult caregivers (2011+)

# DATA-INTENSIVE RESEARCH CONFERENCE

Pre-conference workshop  
presented by **IPUMS** and **NDiRA**

## Structure of Time Diary Data

START	STOP	ACTIVITY	LOCATION	WITH WHOM
4:00	6:00	Sleep	n/a	n/a
6:00	6:10	Personal Care	n/a	n/a
6:10	6:15	Dressing	Home	Alone
6:15	6:30	Dressing Household Adult	Home	Spouse
6:30	6:45	Preparing meal	Home	Alone
6:45	6:55	Eating meal	Home	Spouse
6:55	7:30	Cleaning up after meal	Home	Alone
7:30	10:00	Watching television	Home	Spouse
10:00	11:00	Napping	Home	n/a
11:00	11:05	Personal Care	Home	n/a
11:05	12:00	Yardwork	Home	Alone

## Identifying Adult Caregivers

1. Activity-based: ATUS respondents who provide care to adults on the day they respond to the survey
  - Based only on activities reported in the time diary
  - Why this approach is problematic:
    - It misses people who don't provide care daily
    - Some activities caregivers perform are for other people (e.g., preparing meals, laundry) but would not be classified as caregiving in the ATUS
2. Based on survey question: ATUS respondents who provided care to adults in the 3 months prior to the survey
  - More inclusive identification of caregivers



## Comparing Eldercare Identification Strategies

- 2021 ATUS data
  - Activity based: Diary day adult care providers 938
  - Survey based: Adult care providers in the last 3 months 1,540
    - If yes, adult care providers yesterday 410
      - Nearly 5,000 respondents provided care yesterday between 2011 and 2021

## More Caregiving Data

- Number of persons to whom the respondent provided care in the last 3 months ([ECNUM](#))
- Frequency of care provision in the last 3 months ([ECFREQ](#))
- Details related to care recipients
  - Whether they are co-resident ([HH\\_EC](#))
  - Relationship to respondent ([RELATER](#))
  - Age ([ECAGE](#))
  - Years care provided ([ECYEAR](#))
  - Months of care provided ([ECMONTH](#))

## Grandparent Care

- Detailed information on who respondents are with enables identifying time with co-resident grandchildren and/or with non-resident family members under 18
- Hundreds of ATUS respondents report living with grandchildren each year
- Analyze how much time is spent with grandchildren/non-resident children under 18 and what kinds of activities they do together

## Studying Caregivers Using the ATUS

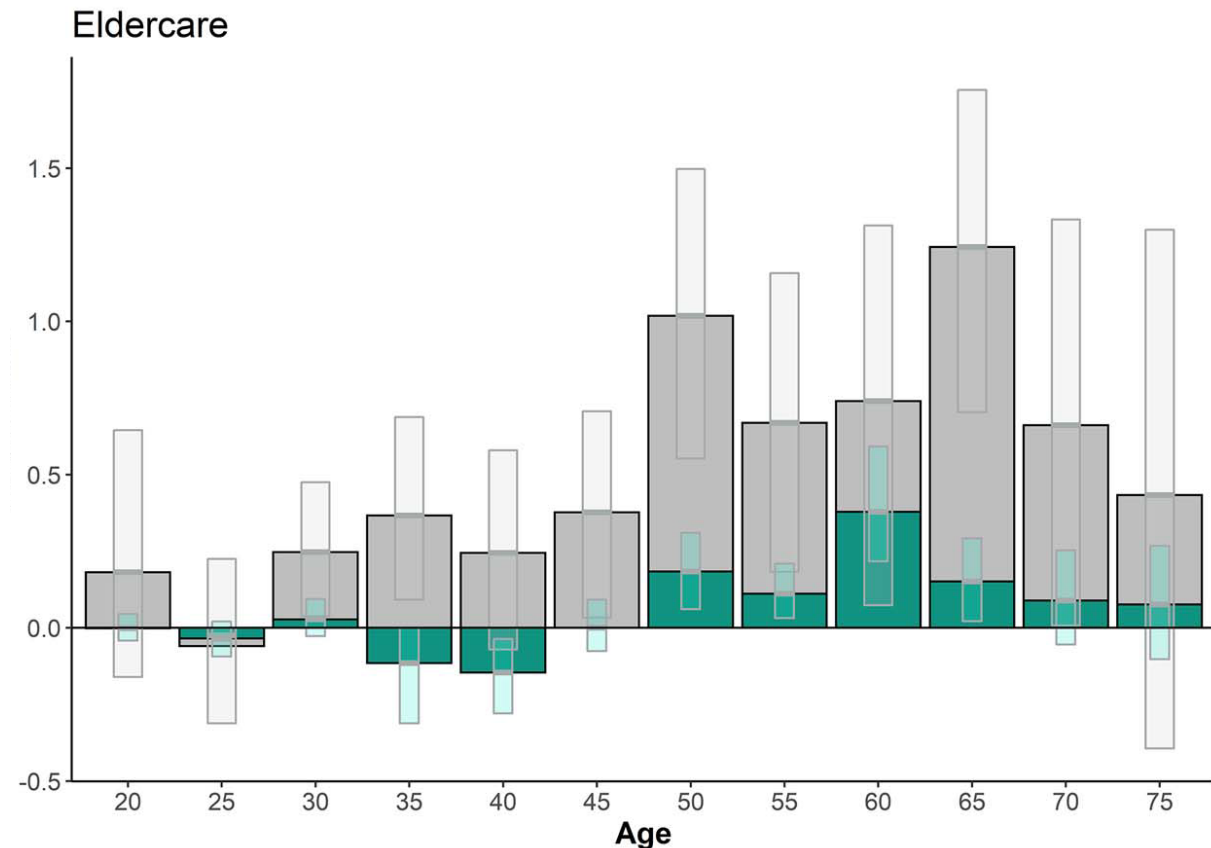
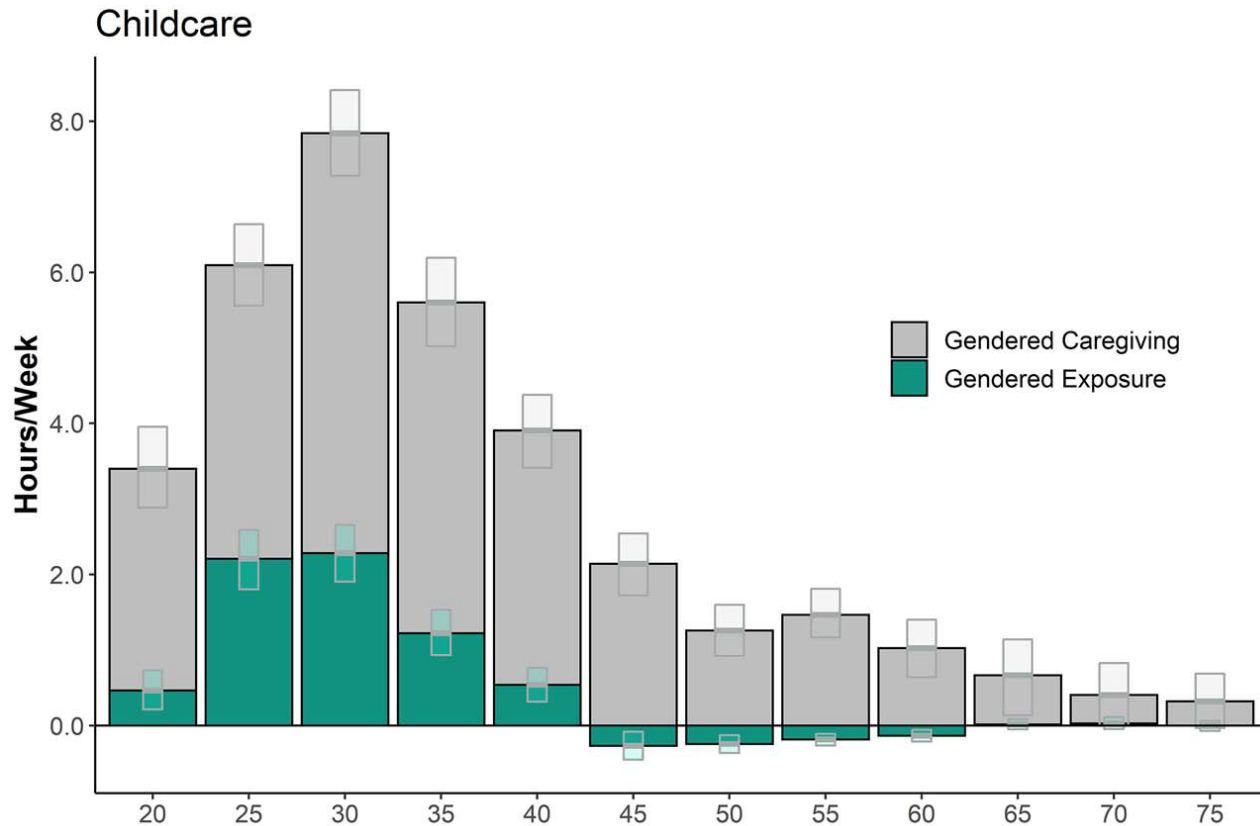
- Demographic profiles of caregivers
- Caregiving profiles of caregivers
- Comparisons of time use based on
  - Whether care is provided to a spouse, child, parent, or non-household member
  - Whether one provides care to adults, young children, or is employed
  - Holding multiple roles (caregiver, spouse, parent, employee)
- Experiences of stress, happiness, sadness, pain, fatigue, and meaning on the diary day and in the context of caregiving and other activities

## Illustrations: Using ATUS to Study Caregiving

- [Racial/Ethnic Differences in Caregiving Frequency: Does Immigration Status Matter?](#)
- [Patterns of Caregiving and Work](#)
- [Bringing Family Demography Back In: A Life Course Approach to the Gender Gap in Caregiving in the United States](#)
- [Differences in the experiential well-being of Hispanics and non-Hispanics engaged in elder care](#)
- [Evaluative and Experienced Well-Being of Caregivers of Parents and Caregivers of Children](#)

# DATA-INTENSIVE RESEARCH CONFERENCE

Pre-conference workshop  
presented by **IPUMS** and **NDiRA**



Source: Erin Ice. 2022. Bringing Family Demography Back In: A Life Course Approach to the Gender Gap in Caregiving in the United States. *Social Forces*.

<https://doi.org/10.1093/sf/soac041>

## Additional Opportunities

- Identify plausible caregivers
  - Detailed information on all household members
- Identify individuals in care providing occupations
  - Rich information on occupation and industry

## Identify Plausible Caregivers



Partner Child

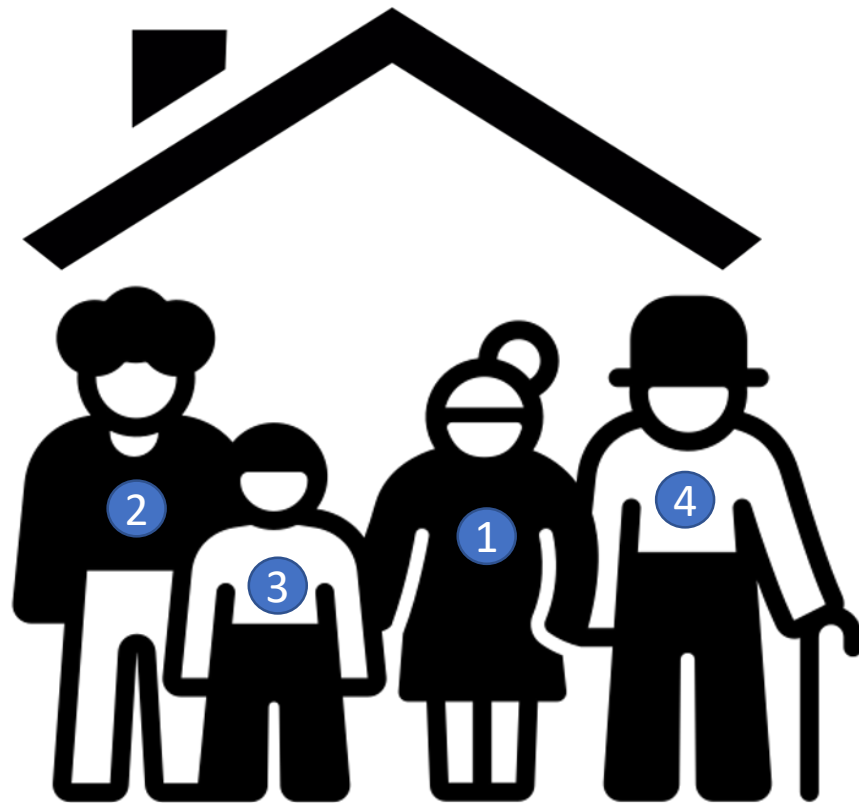
Respondent

Father

- Most IPUMS microdata both
  - contain data on entire households
  - specify relationships between the main respondent and other household members
- Use characteristics of household members to identify plausible caregivers
  - Co-resident parent with a difficulty (e.g., remembering, walking or climbing stairs)
  - Spouse with a difficulty
  - Non-employed adult child with one or more difficulties



## IPUMS Family Interrelationships



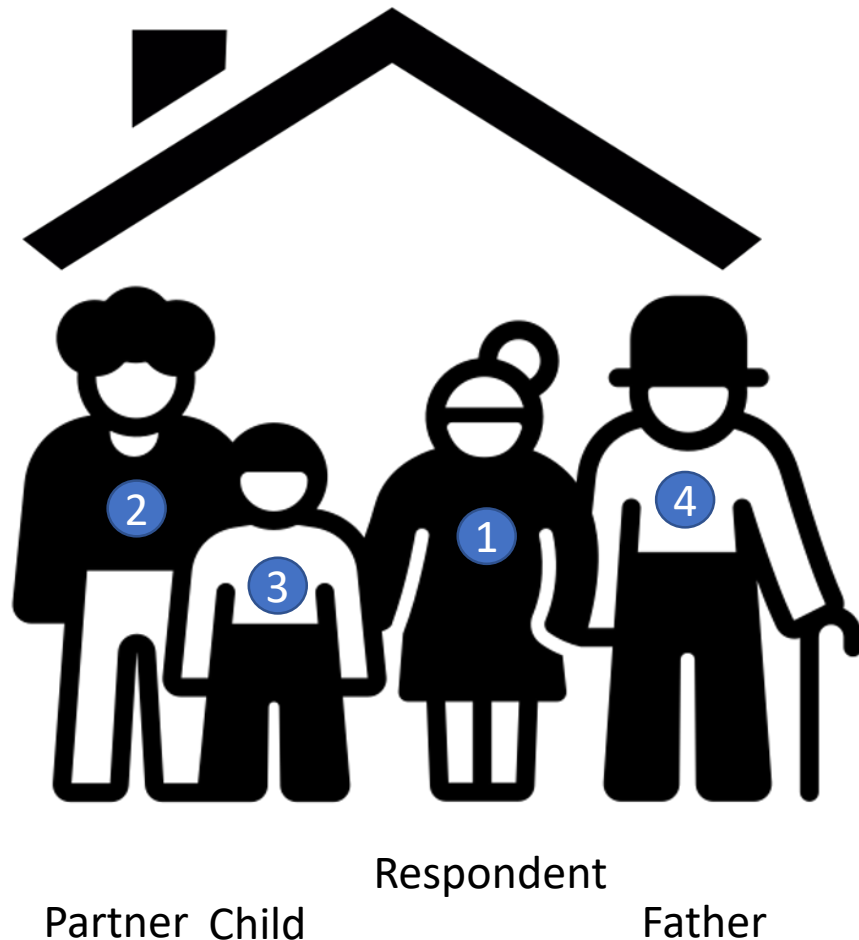
Partner Child

Respondent

Father

- Use identified relationships to make parent/child and spouse/partner links explicit
  - Relationships to person 1
    - Partner: 2
    - Father: 4
  - Relationships to person 2
    - Partner: 1
  - Relationships to person 3
    - Mother: 1
    - Father: 2

## IPUMS “Attach Characteristics” Feature



- Use explicit parent/child links to put information about parents on child records
- Use explicit partner/spouse links to put information about partner/spouse on partner/spouse records
- Example: father has difficulty walking; use attach characteristics to put this information about father on daughter’s record

# DATA-INTENSIVE RESEARCH CONFERENCE

Pre-conference workshop  
presented by **IPUMS** and **NDiRA**



## ATTACH CHARACTERISTICS ([HELP](#))

Check the boxes below to make one or more new variables describing the characteristics of other persons in the household. For example, checking the "Spouse" box next to the AGE variable would produce a variable called AGE\_SP, which would specify the age of each respondent's spouse.

Checking the "Father" or "Mother" boxes will produce two new variables describing the characteristics of a person's parents. For example, checking the "Mother" box next to AGE would produce AGE\_mom and AGE\_mom2 which would specify the age of both parents for a child with two female parents. For a child with one female parent, AGE\_mom2 will be missing.

In samples before 1970, IPUMS family interrelationship variables do not link same-sex couples. In these samples, the attached characteristics for the second mother and second father will all be blank.

Variable	Head	Father	Mother	Spouse
<a href="#">PERNUM</a>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<a href="#">PERWT</a>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<a href="#">AGE</a>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<a href="#">HIGRADE</a>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<a href="#">HIGRADED</a>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<a href="#">EMPSTAT</a>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<a href="#">EMPSTATD</a>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

SUBMIT

## Availability of Attach Characteristics Feature

- ✓ USA
- ✓ International
- ✓ CPS
- ✓ ATUS
- ✓ NHIS
- × MEPS

# DATA-INTENSIVE RESEARCH CONFERENCE

Pre-conference workshop  
presented by **IPUMS** and **NDiRA**

Questions?



## Other Time-Diary-Based Caregiving Resources

- [National Survey of Caregivers](#)
  - 2011, 2015, 2017, 2021+
  - Rich information on caregivers linked to information on care recipients

