Description

Final Trend ID Number - All Cases

Year of data collection

Trended final status flag: 2015 and 2020 projects

Trended qualified flag: 2015 and 2020 projects

Trended dispo code: 2015 and 2020 projects

Trended fully screened flag: 2015 and 2020 projects

Sample

Mode of data collection

S1a - Caregiver of adult - screener with initial respondent

S1b - Caregiver of Child - screener with initial respondent

S1c - Were any adults care/cared for age 50+

S2 - Age of initial respondent - online from panel, phone was asked

S2b - Age ranges of initial respondent

SC4 - Race/Ethnicity of initial respondent mention1

SC4 - Race/Ethnicity of intial respondent mention 2

S4b - Are you of Asian origin, background, or descent, including the regions of the Indian subcontinent, Far East, Southeast Asia, or Pac

S5 - Gender of initial respondent

Hispanic status of initial respondent - created (no data for Asian phone sample 2015)

Race/ethnicity of initial respondent single punch - created

Age of initial respondent

S6 - Number of people living in household

S7 - Householder status of initial respondent

SC8 - Are you related to anyone else who lives with you (if HHer only)?

SC9 - Is householder related to anyone else who lives in HH (if not HHer)?

S10 - Age of householder if not initial respondent

S11 - Trended created Hispanic origin of householder if not initial respondent

S11a - Hispanic ethnicity of householder if not initial respondent - fielding version

S12 - White - Householder race if not initial respondent

S12 - Black/African-American - Householder race if not initial respondent

S12 - American Indian/Alaska Native - Householder race if not initial respondent

S12 - Asian - Householder race if not initial respondent

S12 - Native Hawaiian/Pacific Islander - Householder race if not initial respondent

S12 - 2+ Races - Householder race if not initial respondent

S12 - Refused - Householder race if not initial respondent

Household size - created

Householder status of Initial respondent - created

Type of household family or not - created

Householder - Hispanic status

Householder - Race/Ethnicity single punch

Householder - Age

Householder - Age categorical 7 categories

S13 - Request to speak to caregiver (landline phone sample only)

S14a - Confirmation of Caregiver of Adult with caregiver who is not initial respondent (landline phone sample only)

S14b - Confirmation of Caregiver of Child with caregiver who is not initial respondent (2020 landline phone sample only)

Final Caregiver Status flag at Household Level

Age of caregiver - created

Age of caregiver categorical - created

Hispanic status of caregiver - created

Race/ethnicity of caregiver single punch - created

Gender of caregiver - created

Q2 - Number of adults/children cared for in past 12 months

Q3 - Are all recipients together in an institutional setting (if cares for 5 or more)

Q4 - How many recipients had some sort of special need (if cares for 5 or more)

Q2B - Corrected number of adults/children cared for in past 12 months

Final number of Care Recipients

Q1 - Current or past caregiver

Age of Main Care Recipient - created

Age of Main Care Recipient categorical - created

Type of caregiver - adult or child main recipient - created

Care recipient gender

Q7 - Relationship of recipient to caregiver

Q11 - Distance where CR lives

Q12 - Frequency that caregiver visits recipient [if not in same household]

Q13 - Location where recipient lives [if not in same household]

Q14C - Did/Does recipient live alone [if not in same household]

Where recipient lives - created

Does recipient live with caregiver - created

Q15 - Did/Does recipient live in a rural area

Q16b - caregiver lives in a rural area (created from panel info online; asked on phone)

Q17a - Short term physical condition - recipient needs care because of

Q17b - Long term physical condition - recipient needs care because of

Q17c - Emotional or mental health problem - recipient needs care because of

Split Sample on Q17 [2020 only] - different wording versions shown

Q17d - Developmental or intellectual disorder [2020 only, both split wordings] - recipient needs care because of

TREND Q17d - Developmental or intellectual disorder or mental retardation [2015 and 2020]

NEW Q17d - Developmental or intellectual disorder or delay [2020 new]

Q17f - Behavioral issue - recipient needs care because of

Q17g - Memory problem - recipient needs care because of

Q17 Count of conditions selected - created

Split Sample on Q18 [2020 only] - different wording versions shown

Q18 - Main problem or illness recipient requires/ed care for

Q19 - Is/Was child recipient limited in ability to do things most children of same age do? [caregivers of children only, 2020]

Q20 - Does/Did recipient have Alzheimer's or other mental confusion [if not mentioned in Q18]

Whether recipient has Alzheimer's or dementia - created from Q18/Q20

Q20b - Recipient has Parkinson's? [2015 only]

Presence of Parkinson's - created [2015 only]

Q21 - Length of caregiving period for recipient

Length of time provided care all life replaced with recipient age - created

Length of time provided care to use for means - created

Length of time cared - categorical - created

Q22a - Get in and out of beds and chairs [ADL], help/ed recipient [if older than 2]?

Q22b - Get dressed [ADL], help/ed recipient [if older than 3]?

Q22c - Get to and from the toilet [ADL], help/ed recipient [if older than 3]?

Q22d - Bathe or shower [ADL], help/ed recipient [if older than 5]?

Q22e - By dealing with incontinence or diapers [ADL], help/ed recipient [if older than 3]?

Q22f - By feeding him or her [ADL], help/ed recipient [if older than 2]?

Count of ADLs

N1 - Difficulty of helping recipient with ADLs [if does at least 1 ADL]

Q22g - By giving medicines, pills, or injections [IADL], help/ed recipient [all]?

Q23a - Managing finances, such as paying bills or filling out insurance claims [IADL], help/ed recipient [all]?

Q23b - Grocery or other shopping [IADL], help/ed recipient [if adult]?

Q23c - Housework, such as doing dishes, laundry, or straightening up [IADL], help/ed recipient [if adult]?

Q23d - Preparing meals [IADL], help/ed recipient [if adult]?

Q23e - Transportation [IADL], help/ed recipient [if adult]?

Q23f - Arranging outside services, such as nurses, home care aides, or meals-on-wheels [IADL], help/ed recipient [all]?

Count of IADLs

N2 - Had problems dealing with bank or credit union when helping recipient? [if manages finances, 2015 only]

M8 - Time Consuming to help with finances, bills, insurance claims [if provided help, 2020 only]

Q23g - Advocating for them with providers, services, [schools], agencies

Q23i - Monitoring severity of condition to adjust care accordingly

Q23j - Communicating with health care professionals about their care

Count of caregiving support activities - cargivers of children only [NEW 2020]

Q25 - Hours per week spent caregiving

Hours of care provided use for mean - created

Categorical hours of care provided - created

Lower v Higher hours of care provided - created for banner

Level of Care Index 5 levels - created

Level of Care Index 3 collapsed categories - created

Q25z - How much care given in a normal week [if constant care, NEW 2020]

N3 - Helped recipient with medical nursing tasks

N4 - How difficult to do medical/nursing tasks? [2015 only]

N5 - Did anyone prepare you to do medical/nursing tasks? [2015 only]

N6 - Person who prepared you to do medical/nursing tasks - coded mention1 [2015 only]

N6 - Person who prepared you to do medical/nursing tasks - coded mention2 [2015 only]

N6 - Person who prepared you to do medical/nursing tasks - coded mention3 [2015 only]

N7 - How well do you feel that person prepared you to take on medical/nursing tasks? [2015 only]

N8 - Preferred method of learning Medical/Nursing task mention1 [2015 only]

N8 - Preferred method of learning Medical/Nursing task mention2 [2015 only]

N8 - Preferred method of learning Medical/Nursing task mention3 [2015 only]

N8 - Preferred method of learning Medical/Nursing task mention4 [2015 only]

N8 - Preferred method of learning Medical/Nursing task mention5 [2015 only]

N8 - Preferred method of learning Medical/Nursing task mention6 [2015 only]

N8 - Preferred method of learning Medical/Nursing task mention7 [2015 only]

N8 - Preferred method of learning Medical/Nursing task mention8 [2015 only]

N8 - Preferred method of learning Medical/Nursing task mention9 [2015 only]

N9 - In the last 12 months how many times was recipient hospitalized overnight

N10 - Were you included by health care workers in discussions about their care? [2015 only]

N11 - Before discharge did you receive clear instructions about medical/nursing tasks? [2015 only]

Q28 - Anyone else provided unpaid help to recipient in past 12 months

Q29 - Who is main unpaid caregiver [if other caregivers]

Primary caregiver status - created

Primary caregiver status detailed - created

Q29z - Any children providing unpaid care to recipient [if other caregivers, 2020 only]

Q30 - Recipient received paid help in past 12 months (aides, housekeepers, or other people)

Q38 - Ease to coordinate care between recipients healthcare and service providers?

N12 - Expects to be caregiver to someone over next five years

Q35 - Physical strain caring for recipient is/was [scale of 1 to 5]

Q36 - Emotional stress caring for recipient is/was [scale of 1 to 5]

Q37b - Financial strain caring for recipient is/was [scale of 1 to 5]

Q39 - Feels had a choice to take on caring for recipient

Whether caregiver had a choice - created

M5a - Role as caregiver gives/gave sene of purpose or meaning in life (agree/disagree) - New 2020

M5b - I find/found it difficult to take care of my own health (agree/disagree) - New 2020

M5c - I feel/felt alone (agree/disagree) - New 2020

Q32A - Are you currently employed?

Q33 - Employed in past year while caregiving [if past caregiver or current caregiver but not currently employed]

Ever employed in past year while also a caregiver - created

N13 - Hours worked per week on average while caregiver [if worked and cared in past year]

Q33Z - Work payment arrangement [if worked and cared in past year] - NEW 2020

N13B - Self employment status [if worked and cared in past year]

N14 - Supervisor knew/knows you were/are a caregiver [if worked and cared in past year]

N16a - Flexible work hours offered at work [if worked and cared in past year]

N16b - Telecommuting or working from home offered at work [if worked and cared in past year]

N16c - Programs like information, referrals, counseling or EAP offered at work [if worked and cared in past year]

N16d - Paid [new 2020: family] leave offered at work [if worked and cared in past year]

N16e - Paid sick days offered at work [if worked and cared in past year]

N16f - Unpaid family leave offered at work [if worked and cared in past year] - NEW 2020

N16 count of benefits- TRENDED - includes only items A-E [employed caregivers only]

N16 count of benefits total - use for 2020 only - items A-F [employed caregivers only]

Q34a - Did you ever: Went in late, left early, or took time off during day to provide care [if worked and cared in past year]?

Q34b - Did you ever: Took a leave of absence [if worked and cared in past year]?

Q34c - Did you ever: Went from working full- to part-time or cut back hours [if worked and cared in past year]?

Q34d - Did you ever: Turn down promotion [if worked and cared in past year]?

Q34e - Did you ever: Lost any job benefits [if worked and cared in past year]?

Q34f - Did you ever: Gave up working entirely [if worked and cared in past year]?

Q34g - Did you ever: Retire early [if worked and cared in past year]?

Q34h - Did you ever: Receive warning about performance or attendance [if worked and cared in past year]?

Q34 - Count of workplace accomodations made

M2 - At any time while caregiving did you work or have a job [if has not worked and cared in past year] - NEW 2020

N15 - Reason for leaving job: Needed more time to care for person [2020 only]

N15 - Reason for leaving job: Could not afford paid help for person [2020 only]

N15 - Reason for leaving job: Job did not allow flexible work hours [2020 only]

N15 - Reason for leaving job: Job did not allow time off with pay [2020 only]

N15 - Reason for leaving job: Other reason [2020 only]

N15 - Reason for leaving job: Did not leave job, just took leave of absence [coded, 2020 only]

N15 - Reason for leaving job: Retired [coded, 2020 only]

N15 - Reason for leaving job: Refused, No Answer [2020 only]

N15 - Reason for leaving job: Injury, sick, disabled [coded, 2020 only]

N15 - Reason for leaving job: Fired, laid off [coded, 2020 only]

N15 - Reason for leaving job: Needed more time to care for person [2015 only]

N15 - Reason for leaving job: Could not afford paid help for person [2015 only]

N15 - Reason for leaving job: Job did not allow flexible work hours [2015 only]

N15 - Reason for leaving job: Job did not allow time off with pay [2015 only]

N15 - Reason for leaving job: Other reason [2015 only]

N15 - Reason for leaving job: Did not leave job, just took leave of absence [coded, 2015 only]

N15 - Reason for leaving job: Retired [coded, 2015 only]

N15 - Reason for leaving job: Refused, No Answer [2015 only]

M3 - Ever felt role as caregiver led to penalized or discriminated at work - NEW 2020

N17 - Ever been fired from any job as a result of being caregiver for anyone? [2015 only]

N18 - Support ban workplace discrimination against workers with caregiving responsibilities? [2015 only]

Q45a - Ever Requested inforamtion about financial help for recipient

Q45b - Ever Used respite services

Q45c - Ever Had outside service provide transportation for recipient

Q45d - Ever Made modifications to recipient's home

Q45e - Ever Had doctor, nurse, social work ask what you need/ed to care for recipient

Q45f - Ever Had doctor, nurse, social work ask waht you need/ed to care for self

N19 - Difficulty of getting affordable services in recipient local area

N20 - Requiring provider to include your name on recipient medical chart - 2015 only

N20 - Requiring hospitals to inform you about major decisions - 2015 only

N20 - Requiring hospitals/facilities to instruct on medical/nursing tasks - 2015 only

N20 - Having respite services available (Helpful caregiver support) - trendable

N20 - Requiring doctor, nurse, social work to ask about what you need/ed to care for recipient (Helpful caregiver support) - trendable

N20 - Requiring doctor, nurse, social work to ask what you need/ed to care for self (Helpful caregiver support) - trendable

N20 - None of the above are Helpful caregiver support [2020 only]

N20 - Refused are Helpful caregiver support [2020 only]

M1 - Doctor or health care professional (Used for caregiver help or info) - NEW 2020

M1 - Friends or family (Used for caregiver help or info) - NEW 2020

M1 - Government agenies or organizations (Used for caregiver help or info) - NEW 2020

M1 - Hospital or other care facility (Used for caregiver help or info) - NEW 2020

M1 - Online or social media (Used for caregiver help or info) - NEW 2020

M1 - Organization or non-profit for aging, caregiving, or specific condition (Used for caregiver help or info) - NEW 2020

M1 - Religious organization (Used for caregiver help or info) [coded, 2020 only]

M1 - Somewhere else (Used for caregiver help or info) - NEW 2020

M1 - Not applicable: never got help or info - NEW 2020

M1 - Refused (Used for caregiver help or info) - NEW 2020

M7a - Had virtual or online visit with healthcare provider for recipient (ever done online) - NEW 2020

M7b - Created online or shared calendar to organize caregiving schedules or activities (ever done online) - NEW 2020

M7c - Managed recipient's prescription refills or delivery on app or website (ever done online) - NEW 2020

M7d - Placed online order for groceries or household supplies for recipient (ever done online) - NEW 2020

M7e - Used ride service like Lyft or Uber for recipient (ever done online) - NEW 2020

M7f - Searched online for support services, aides, facilities, or other help for recipient (ever done online) - NEW 2020

M7g - Connected with other caregivers online using social media or support groups (ever done online) - NEW 2020

M7h - Watched videos to learn how to do different things for recipient (ever done online) - NEW 2020

M11a - Created electronic lists or spreadsheets to track care activities (ever done using tech) - NEW 2020

M11b - Checked up on recipient using app, video, wearable, or remote monitoring (ever done using tech) - NEW 2020

M11c - Tracked recipient's personal health records (ever done using tech) - NEW 2020

M11d - Tracked recipient's finances (ever done using tech) - NEW 2020

M11e - Got or used assistive devices for things like recipients low vision or hearing problems (ever done using tech) - NEW 2020

Q48a - Keeping recipient safe at home - needs more help/info [2020 only]

Q48b - Managing recipient's challenging behaviors - needs more help/info [2020 only]

Q48c - Activities you could do with recipient - needs more help/info [2020 only]

Q48d - Choosing home care agency, assisted living facility or nursing home - needs more help/info [2020 only]

Q48L - Managing your emotional or physical stress - needs more help/info [2020 only]

Q48m - Making end of life decisions - needs more help/info [2020 only]

Q48n - Finding non-English language educational materials - needs more help/info [2020 only]

Q48e - Figuring out forms, paperwork, or eligibility for services or support for recipient - needs more help/info [2020 only]

Q48f - Managing or handling own finances - needs more help/info [2020 only]

Q48g - Using technology to care for recipient - needs more help/info [2020 only]

Q48 - Some other type of help or info needed [2020 only]

Q48a - Keeping the person you care for safe at home - need more help/info [2015 only]

Q48b - Managing challenging behaviors, such as wandering - need more help/info [2015 only]

Q48c - Managing incontinence or toileting problems - need more help/info [2015 only]

Q48L - Managing your emotional and physical stress - need more help/info [2015 only]

Q48m - Making end-of-life decisions - need more help/info [2015 only]

Q48e - Finding non-English language educational materials - need more help/info [2015 only]

N21 - Does/Did recipient/recipient's family have plans in place for future care?

N22 - Do you have your own plans for your future care?

M6a - Took on more debt (financial impact of caregiving) - NEW 2020

M6b - Missed or was late paying for student loan (financial impact of caregiving) - NEW 2020

M6c - Borrowed money from family or friends (financial impact of caregiving) - NEW 2020

M6d - Filed for bankruptcy (financial impact of caregiving) - NEW 2020

M6e - Been unable to afford basic expenses like food (financial impact of caregiving) - NEW 2020

M6f - Left bills unpaid or paid late (financial impact of caregiving) - NEW 2020

M6g - Used up personal short-term savings (financial impact of caregiving) - NEW 2020

M6h - Used up long-term savings to pay for other things (financial impact of caregiving) - NEW 2020

M6i - Stopped saving (financial impact of caregiving) - NEW 2020

M6j - Moved to less expensive home, apartment, place (financial impact of caregiving) - NEW 2020

M6k - Was evicted or had home foreclosed (financial impact of caregiving) - NEW 2020

M6L - Put off when you planned to retire or decided to never retire (financial impact of caregiving) - NEW 2020

M6m - Had to start working, work more, find second job (financial impact of caregiving) - NEW 2020

M6 summary - had at least one Savings impact [2020 only]

M6 summary - had at least one Debt impact [2020 only]

M6 summary - had at least one Bills impact [2020 only]

M6 summary - had at least one Home impact [2020 only]

M6 summary - had at least one Work impact [2020 only]

M9a - Income tax credit to caregivers to offset cost of care (helpfulness of policy) - NEW 2020

M9b - Partially paid leave of absence for work (helpfulness of policy) - NEW 2020

M9c - Program where caregivers could be paid for hours of care (helpfulness of policy) - NEW 2020

Q47x - Most helpful financial policy [if more than one was helpful in M9] - NEW 2020

Q47x - Most helpful financial policy backfilled from M9 sereis [2020 only]

Q47A - Financial policy most helpful [2015 only]

M10 - Was student in past year while providing care - NEW 2020

D1 - Caregiver health status [at time of caregiving]

D2 - Impact of caregiving on caregiver health status

M12 - Caregiver has health insurance [at time of caregiving]? - NEW 2020

M13 - Caregivers main source of health insurance - NEW 2020

Marital status of caregiver at time of caregiving - created

D6 - Caregiver had children living in home [at time of caregiving]

D4 - caregiver served in military - created (online) and asked (phone)

D5 - Care recipient ever served in US Armed Forces [if adult recipient]

D5b - Did recipient serve before 9-11-01 (if veteran; 2015 only)?

Caregiver Education highest grade completed - created

Caregiver Household Income - created [in each year's dollars, no adjustment]

Caregiver Household Income MidPoint values - full information as provided from panel/respondent and 2014 inflation adjusted

Caregiver Household Income MidPoint values - collapsed scales to match 2019 to 2014 and 2014 inflation adjusted

Has Internet Access in home? - online respondents only

Identifies as Lesbian, Gay, Bisexual, other sexual orientation, Transgender, and/or other gender identity

Language of Survey

Household Weight - Use for household prevalence only with base study samples only (smptyp14<5)

Individual Weight - Use for Results and Population Prevalence with base study samples only (smptyp14<5)

Individual level Asian Caregivers weight - use for cases ASFLAG=1 only

Individual level Caregivers age 65 plus weight - Use if OLDflag=1 or 2 only

Individual level Caregivers age 65-74 weight - Use if OLDflag=1

Individual level Caregivers age 75 plus weight - Use if OLDflag=2

Asian caregiver flag

Older Caregiver flag (age 65+)

Trended validated caregiver flag: 2015 and 2020 projects