Department for Education

The lives of young carers in England

Omnibus survey report

Appendices to research report

January 2017

Sarah Cheesbrough, Carrie Harding, Hannah Webster and Luke Taylor - Kantar Public

With Professor Jo Aldridge - Young Carers Research Group, Loughborough University

GSR
GOVERNMENT SOCIAL RESEARCH
Social Science in Government

Contents

Appendix A. Defining young caring 3

Reviewing the definitions 3

Appendix B – Selecting a minimum age to interview young carers directly 9

Appendix C. Literature Review 12

Appendix D. Sampling Method 16

The Kantar TNS Face to Face Omnibus 18

Appendix E. QAS-99 19

Appendix F. Cognitive Testing 34

F.1 Methodology 34

F.1 Single question about young caring 35

D.2 Prevalence questions 39

Appendix G. Final Questionnaire – Young Carers & Comparison survey 53

Appendix H. Survey questions on the nature and impact of caring responsibilities 94

Appendix A. Defining young caring

In the feasibility study we reviewed a range of definitions used to identify a young carer in the legislative, practitioner and research fields. We then attempted to operationalise this definition for this reseach in a way that could be applied in either a large scale self-completion or interviewer administered survey as well as qualitative research to support that survey evidence.

Reviewing the definitions

A definition of young caring needs to incorporate key dimensions of young caring that are important in academic discourses and in health and social care policy and practice. At the same time, it needs to enable children and young people with complex needs to be identified as young carers (and may themselves also be able to self-identify as young carers). It needs to be concise to be applied effectively in the research context, but it must not be too broad (overlooking the specific dimensions and factors that delineate the young caring experience). It should not, however, be too narrowly focused to the exclusion of particular dimensions of caring that may be important to children and young people themselves who are, or could be, carers and who may have multiple or complex needs.

Legislative

The research was designed to support the implementation of the Children and Families Act 2014, which requires local authorities to identify young carers and assess their support needs. It defines a young carer as

> *a person under 18 who provides or intends to provide practical or emotional support to another person*.[1]

The Act includes a section on assessments for young carers and refers to the Children Act 1989, although this provides a similarly broad definition that a

> '*young carer' means a person under 18 who provides or intends to provide care for another person*[2]

---

[1] Children and Families Act, 2014, c6, Part 5, Young Carers and Parent Carers, Section 96 (3) Enacted http://www.legislation.gov.uk/ukpga/2014/6/section/96/enacted

[2] http://www.legislation.gov.uk/ukpga/1989/41 17ZA (3)

The Care and Support Statutory Guidance issued under the Care Act 2014[3] sets out the ways in which young carers are identified and provided with the support that they need but includes no further definition. Prior to these two new Acts, the Government's 2008 National Carers' Strategy included young carers in its provisions but did not provide its own definition beyond accepting the 2001 Census estimates of the number of young carers and time spent caring.

Practitioner

In their template for a local Memorandum of Understanding, ADASS, ADCS and the Children's Society state that:

> *The term young carer should be taken to include children and young people under 18 who provide regular or ongoing care and emotional support to a family member who is physically or mentally ill, disabled or misuses substances…A young carer becomes vulnerable when the level of care-giving and responsibility to the person in need of care becomes excessive or inappropriate for that child risking impacting on his or her emotional or physical well-being or educational achievement and life chances*[4].

This definition is both inclusive and specific (for example, by referencing substance misuse), incorporates the extent or duration of care provision ('regular' and 'ongoing', although it does not define these terms) and refers to the impact of caring on children (but without defining what is meant by 'vulnerable', 'excessive' or 'inappropriate').

In their guidance for professionals on working with young carers and their families, the Carers Trust uses a shorter definition[5] which is then further clarified by examples:

> *Young carers are children and young people who often take on practical and/or emotional caring responsibilities that would normally be expected of an adult.*
>
> *Some of the ways young people care for someone are:*
>
> - *Staying in the house a lot to be there for them*
> - *Helping them to get up, get washed or dressed, or helping with toileting*

---

[3] https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/315993/Care-Act-Guidance.pdf

[4] ADASS, The Children's Society, ADCS (2012) Working together to support young carers and their families: a template for a local memorandum of understanding between Statutory Directors of Children's Services and Adult Social Services http://www.adcs.org.uk/download/position-statements/2012/MoU%20young%20carers%202012.pdf

[5] https://professionals.carers.org/who-are-young-carers

- *Doing lots of the household chores like shopping, cleaning and cooking*
- *Looking after younger brothers and sisters*
- *Providing emotional support or a shoulder to cry on*

This definition is both broad and specific, although it does not take into account the age of children who care, the context of caring (ie that caring becomes necessary for children when parents or other relatives in or outside the home are ill or disabled), nor the impact of caring on children.

In professional guidance on assessing children in need, Dearden and Aldridge (2009) [6] refer to young carers as,

> *children and young people, under the age of 18, who provide care or support to a relative in the home. That relative is usually a parent but may be a sibling, grandparent or other family member'*

The guidance then goes on to describe the context of caring (that is, when a family member becomes ill or is disabled) and the appropriate and necessary assessment procedures required when children are identified as carers.

Bringing together many of the definitional issues, Becker (2000: p378)[7] has described young carers as:

> *children and young persons under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility that would usually be associated with an adult. The person receiving care is often a parent but can be a sibling, grandparent or other relative who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision.*

UK and international research

In comparable international literature, definitions of young caring are most prominent in research, policy and practice in those countries which have the most developed national carers' strategies, namely the UK, US, Australia and Sweden. Definitions have been

---

[6] Dearden, C. and Aldridge, J. In J Howarth (ed) (2009) *The Child's World, The Comprehensive Guide to Assessing Children in Need* (2nd edition), Jessica Kingsley Publishers, pp 214-228.
[7] Becker, S. In M Davies (ed) *The Blackwell Encyclopedia of Social Work* (2000) cited in Social Care Institute of Excellence (2005) *The health and well-being of young carers,* SCIE Research Briefing 11 http://www.scie.org.uk/publications/briefings/briefing11/

developed based, in the main, on the nature of children's caring responsibilities. For example, Diaz et al (2007)[8] identified young carers as:

> *children and adolescents who are 18 years of age and younger and who provide significant or substantial assistance, often on a regular basis, to relatives or household members who need help because of physical or mental illness, disability, frailty associated with aging, substance misuse, or other condition. This assistance may include one or more of the following: personal care, medical care, household management, supervision, translation in medical settings, and emotional support. Young caregivers may provide care directly to the recipient or indirectly by taking over the care recipient's responsibilities, such as parenting younger children. They perform tasks that go beyond chores and require a level of responsibility more appropriate for an adult.*

Similarly, Shifren and Kachorek (2003)[9], in asking American adults about their caring responsibilities in the past, note that

> *respondents must have provided primary caregiving assistance (ie, bathing, feeding, etc.) for a parent or adult relative when the caregiver was under 21 years old*

Although it is sometimes contested in comparable international studies that carers up to age 25 should be considered 'young carers' given shared vulnerabilities[10], most UK studies implement a working definition that a young carer is aged under 18[11] and the Department has commissioned this research consistent with this definition. Whilst there is no formal definition of a minimum age to be a carer, the Census reports caring from age 5 upwards and the Department wished to explore prevalence from this age upwards.

---

[8] Diaz, N., Siskowski, C., & Connors, L. (2007). Latino Young Caregivers in the United States: Who are they and what are the Academic Implications of this Role? Paper presented at the Child & Youth Care Forum

[9] Shifren, K., & Kachorek, L. V. (2003). Does early caregiving matter? The effects on young caregivers' adult mental health. International Journal of Behavioral Development, 27(4), 338-346

[10] For Australia see: Cass, B., Smith, C., Hill, T., Blaxland, M., & Hamilton, M. (2009). Young carers in Australia: understanding the advantages and disadvantages of their care giving. Australian Government, Department of Families Housing, Community Services and Indigenous affairs: Social Policy Research Paper no 38; Ireland, M. J., & Pakenham, K. I. (2010). The nature of youth care tasks in families experiencing chronic illness/disability: Development of the Youth Activities of Caregiving Scale (YACS). Psychology and Health, 25(6), 713-731; for Sweden: Ali, L., Ahlström, B. H., Krevers, B., Sjöström, N., & Skärsäter, I. (2013). Support for Young Informal Carers of Persons with Mental Illness: A Mixed-Method Study. Issues in Mental Health Nursing, 34(8), 611-618.

[11] The use of this definition is reviewed in Becker, S. (2007). Global perspectives on children's unpaid caregiving in the family research and policy on 'young carers' in the UK, Australia, the USA and Sub-Saharan Africa. Global social policy, 7(1), 23-50

Defining caring in a survey

The design of survey questions aimed to operationalise a conceptual definition in a way that was appropriate for the methodology rather than being a stand alone definition that could operate out of this context. We reviewed a number of previous survey approaches in Section 5. However, it is notable to mention here the 2011 UK Census question that applied a wider definition of care recipients to include both non-family members and those outside the household. It asked:

> *Do you look after, or give any help or support to family members, friends, neighbours or others because of either:*
>
> - *long-term physical or mental ill-health/disability?*
> - *problems related to old age?*

Although this definition was more inclusive than those used in many other studies, it was limiting to the extent that it reduced caring to 'long-term physical or mental ill-health/disability [or] problems related to old age' and, thus, excluded a wider range of conditions including substance misuse and mental health problems[12].

Discussion

If the definition of young caring is too general, then important dimensions that delineate the young caring experience are lost. This could result in young carers being identified as vulnerable children in need alongside numerous other vulnerable children (for example, children in care, care leavers, children who experience domestic violence and so on). Some of the definitions described above include terms or dimensions of caring that are ambiguous and thus leave too much room for interpretation (for example, 'regular', 'substantial'). On the other hand, if definitions are too specific or complex then this in itself can be restrictive in terms of how and whether young carers with multiple needs are identified as carers or the extent to which children themselves are able to self-identify as carers.

Some definitions, as described above, include reference to the ages of children who are carers, the amount of care they provide and the impact of this on their lives. Most either refer specifically to care given within the home or do not address context or environment. Only the operational definition used in the 2011 Census explicitly allowed for caring

[12] For further discussion see: The Children's Society (2013). Hidden from View: The experiences of young carers in England: The Children's Society

outside the home. These are all important dimensions of young caring and must be reflected in the definition and data gathering adopted for this study.

In conclusion, we recommended working with the definition that:

> *A young carer is a child/young person under the age of 18 who provides care in, or outside of, the family home for someone who is physically or mentally ill, disabled or misusing drugs or alcohol. The care provided by children may be long or short term and, when they (and their families) have unmet needs, caring may have an adverse impact on children's health, well-being and transitions into adulthood.*

This definition was sufficiently concise for research purposes and recognises the following important dimensions of caring:

- Makes appropriate reference to the legal age of children (ie under the age of 18)
- Refers to the care of an identifiable relative, neighbour or friend.
- Includes care both within and outside the home
- Inclusive in the reasons that someone may need care: involving substance misuse as well as physical or mental illness or disability.
- Refers to the extent or duration of caring (which can be assessed through further screening/testing).
- Refers to the unmet needs of children and families, which, research tells us, is one of the main reasons why children take on care responsibilities in families and why children continue to provide care in the long term.
- Refers to the potential adverse impact of caring on children with respect to their health (which can be physical, mental, emotional health and can be established, through further screening/testing), well-being and transitions into adulthood (on the other hand, caring may also have positive consequences for some children, which can also be established through further screening/testing).

Appendix B – Selecting a minimum age to interview young carers directly

Ethical context

All children and young people under the age of 18 are defined as vulnerable in research governance criteria and guidance, and it is the responsibility of those conducting research with this group to ensure not only that formal and appropriate ethical procedures are followed, but also to work through the potential tensions between the application of research ethics and the issues related to vulnerability that can arise when conducting research with children and young people. The perspectives of the children and young people themselves also need to be taken into account in this process.

Research governance frameworks and ethical guidelines provide extensive guidance about the type and extent of ethical clearance required in order for research studies that include vulnerable or marginalised groups to proceed (Department of Health, 2005[13]; Economic and Social Research Council (ESRC), 2010[14]). However, the identifiers and classifications for vulnerable individuals and groups are somewhat broad here. For example, the Department of Health's (2005) Research Governance Framework for Health and Social Care emphasises participants' capacity and willingness to provide informed consent as well as describes vulnerable or potentially vulnerable participants as children and adults with mental health problems or learning difficulties (2005, p 7). ESRC (2010) descriptors, on the other hand, focus on research that puts participants at 'more than minimal risk' and 'potentially vulnerable groups' as children and young people, those with learning difficulties or cognitive impairments, those who lack the mental capacity to give consent, and 'individuals in a dependent or unequal relationship' (p 8).

In qualitative approaches, research can be tailored in both its design and conduct to enable some of the youngest carers to take part. For a large scale survey, however, we need to be confident that a child taking part in a survey has the maturity to be able to consent to take part in the research, can understand the information provided to be sufficiently reassured about confidentiality and can cognitively process the terms being used in the survey questions to provide an informed response.

---

[13] Department of Health (2005), Research Governance Framework for Health and Social Care, http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_4122427.pdf

[14] Economic and Social Research Council ((ESRC) 2010), Framework for Research Ethics): http://www.esrc.ac.uk/_images/Framework-for-Research-Ethics_tcm8-4586.pdf

Cognitive testing

Given the complexities of both the question to identify a young carer and the questions in the survey itself, after an initial development stage of the questionnaire, in January 2015, Kantar Public[15] researchers conducted face to face cognitive interviews with 15 young carers and seven parents. Participants were sampled from a young carers' support group that worked with carers around the country as well as identifying young carers for interview through Kantar's online survey panel[16]. The interviews tested alternative propositions for questions to identify young caring and used cognitive interviewing techniques to explore both adult and child understanding and interpretation of questions. Children under 10 had unacceptably high levels of cognitive difficulty with terms such as 'caring' and 'household' and reporting of their caring responsibilities to be confident that the survey would be operational on a large scale.

Literature review

We used the principles of Rapid Evidence Assessment to address the question:

> *How effective have different methodologies been in quantitative studies to identify and understand the lives of young carers in England and comparable countries?*

The review selected 48 articles reporting research on young carers. As anticipated, these articles tended to come from the UK, Australia, New Zealand and the United States, though we also found relevant studies from other countries (eg, Sweden, South Africa). To this we added review of the minimum age at which UK national statistics survey conduct interviews directly with children.

We found no examples of large scale surveys conducted directly with carers younger than age 10 and, more commonly in the UK, from age 11 if the young person has taken part in research based within a secondary school. For similar cognitive and ethical reasons considered for this study, some of the largest National Statistics surveys set lower interview limits at age 13 (the Health Survey for England commissioned by the Department of Health), 10 (the Crime Survey for England and Wales commissioned by the Office for National Statistics) or 11 (Taking Part – commissioned by the Department for Culture Media and Sport).

Recommendations adopted for the survey of young carers

To be consistent with previous research the review recommended only asking questions of children who were at least age 10 or 11 and, after review by the Steering Group for

---

[15] Formerly known as TNS BMRB
[16] The panel is managed by Lightspeed Research, part of the Kantar Group

this study, age 11 was taken as the minimum age. For young carers below age 11, the parent interview would be conducted without triangulation against any child survey. The same principles were then adopted for the comparison survey among parents and young people in households not containing a young carer.

Appendix C. Literature Review

We used the Government Social Research principles of Rapid Evidence Assessment (REA) to help us source and synthesise relevant literature on young carers. This is to inform the design of a survey of young carers on behalf of DfE. The review was intended to:

- underpin our proposed methodology to estimate the number of young carers;
- identify any refinements we need to make to the definition of a young carer; and
- assess the quality of previous findings about the lives of young carers.

Our research question to guide us in this review:

> *How effective have different methodologies been in quantitative studies to identify and understand the lives of young carers in England and comparable countries?*

We reviewed both refereed journal articles, book chapters and grey literature that has been published online. We used the following search tools:

- PsycINFO
- SAGE Research Methods Online
- Applied Social Sciences Index and Abstracts (ProQuest)
- International Bibliography of the Social Sciences (IBSS)
- Scopus
- ERIC (Education Resources Information Center)
- eresource@Cambridge (Cambridge University Library)
- British Library Inside
- NSPCC library

As well as these bibliographic databases we reviewed publications and conference papers listed on the websites of:

- Loughborough University Young Carers Research Group (Professor Jo Aldridge) http://www.ycrg.org.uk/
- Professor Saul Becker's personal website http://www.saulbecker.co.uk/
- Young Carers Network from the Carers Trust http://www.youngcarers.net/
- The Children's Society http://www.childrenssociety.org.uk/

For an REA it is important to select search terms that are a balance of "sensitivity (the amount of literature that is found) and specificity (the amount of relevant versus non-

relevant literature found)."[17] In this review, we expected to find a relatively small amount of literature and evidence based on quantitative methods of identifying young carers. As such, our concern was less with excluding studies that were not methodologically robust and more with including only those studies that were relevant to our research question. As such, our search terms (below) are broader than might be seen in other REAs. We searched for papers using the terms:

young + carer* [including *carer*/*carers*]

child* + carer* [including *child/children*]

young + caregiver* [including *caregiver/caregivers*]

child* + caregiver*

young + caring

child* + caring

We did not use the term *care* to avoid retrieving a large volume of literature on looked-after children and care *for* children.

Most REAs apply clear and explicit criteria not only to select studies by their relevance but also to critically appraise the methodological quality of the study as part of the decision over whether to include it in the assessment. However, as we anticipated finding very few papers that met the relevance criteria we did not eliminate any evidence at this stage on methodological grounds. Any methodological weaknesses have been highlighted as part of the review process. Therefore, the only methodological criterion we applied was to select studies that are *quantitative rather than qualitative in nature.*

Using the above method our initial search with each search tool uncovered the following quantitative articles:

- PsycINFO: 132 articles
- SAGE Research Methods Online: 24 articles
- Applied Social Sciences Index and Abstracts (ProQuest): 91 articles
- International Bibliography of the Social Sciences (IBSS) and Scopus (Mendeley): 313 articles
- ERIC (Education Resources Information Center): 26 articles

[17] http://www.civilservice.gov.uk/networks/gsr/resources-and-guidance/rapid-evidence-assessment/how-to-do-a-rea.

- eresource@Cambridge (Cambridge University Library): 160 articles
- NSPCC library: 16 articles
- British Library Inside: no new articles (all articles uncovered in other searches)

Applying our relevance criteria, this resulted in 48 articles to review. As anticipated, these articles tended to come from the UK, Australia, New Zealand and the United States, though we also found relevant studies from other countries (eg, Sweden, South Africa).

The 48 articles we reviewed came from the following search tools; a number of our articles (19 articles) were found across several search tools.

- PsycINFO: 25 articles
- Applied Social Sciences Index and Abstracts (ProQuest): 8 articles
- ERIC (Education Resources Information Center): 5 articles
- eresource@Cambridge (Cambridge University Library): 27 articles
- NSPCC library: 1 article

We located seven articles through our review of publications and conference papers (eg, through the Young Carers Research Group).

These articles and a summary of our review of them can be found in the annexed Excel file provided.

It is worth noting that in the absence of a published report, the survey conducted by the BBC in conjunction with the University of Nottingham in 2010[18] was not available via any of the sources searched and, therefore, not reviewed. From the BBC coverage we know that 4,029 children from 10 secondary schools took part but not how the schools and pupils within those schools were sampled to allow the findings to be grossed up to the estimate that 12% of young people in the UK were carers.

If an even number of interviews were achieved in each school, this amounts to c403 interviews in every school, with serious implications for sampling bias reflecting the very specific local characteristics of the school's pupils and the area. A representative school based sample must take into account type of school (to cover Maintained, Independent and Pupil Referral Units), location and level of deprivation to ensure an appropriate school sampling frame. Although it is practical to sample whole classes within each school to allow teachers to incorporate the completion into the day, with every additional class sampled in a school the bias increases. For example, in the set up of the

[18] http://www.bbc.co.uk/news/education-11757907

Longitudinal Study of Young People in England, an average of 33 pupils in each of 892 school were selected to take part in the study.[19]

Also, although the survey used the respected Multidimensional Assessment of Caring Activities for young carers (MACA YC18) that is discussed in Section 3, the coverage does not report screening information about why the caring is taking place, making it likely that children reported general household responsibilities. Finally, without data collected from the parents, it is not possible to verify the young person's interpretation of the nature of caring that is taking place. The study was therefore deemed insufficiently robust for this review's purposes.

Based on our review, we concluded that random, large-scale, nationally representative surveys, like the SDAC and HILDA in Australia are the most methodologically robust and most suitable for estimating the prevalence of young caring. These surveys in particular rely on established in-person surveys with large sample sizes, though attention must be paid to how questions on young caring are asked (eg, defining caring, time period referred to, etc). The Young Caregivers in the US survey, while laudable for attempting to estimate the number of young carers across the United States, is considerably less robust; its reliance on a postal survey introduces a number of potential issues with a low response rate (as we know is common in postal surveys), and its reliance on parental interviews for all age groups, not just the youngest age groups, could impact the validity of the findings themselves.

Studies that relied on existing young carers projects to provide data or distribute questionnaires are not suitable for estimating the prevalence of young caring; these studies, in addition to achieving low response rates, do not identify hidden carers. Likewise, school-based surveys are not suitable for identifying the prevalence of young caring across a large geographic area (ie, on a national level) as all existing school-based surveys relating to young carers have taken place on a relatively small scale.

[19] http://www.esds.ac.uk/doc/5545/mrdoc/pdf/5545lsype_user_guide_wave_1_to_wave_7.pdf

Appendix D. Sampling Method

The majority of quantitative studies we reviewed used self-completion interviews with young carers themselves. Several studies, particularly those of young carers already in contact with services, used self-completion surveys at the programme site, often in the presence of a project worker or other professional[20]. Conversely, censuses are also self-completion surveys, though not completed in the presence of another individual (ie, an interviewer) who could be asked for assistance or a point of clarification. Several other studies used in-school surveys to collect data on young carers, though all of these studies were largely small-scale (eg, of a local area or city) and none was national in scope[21].

Fewer studies we reviewed used face-to-face interviews with young carers. The Australian Bureau of Statistics Survey of Diability and Caring used face-to-face interviews conducted by trained interviewers, as did the Household, Income and Labour Dynamics in Australia (HILDA) survey[22]. In the Cassidy and Giles study[23] support workers in a young carers' programme administered a survey to their young carer participants, and Burns et al[24] analysed data on young caring from a health survey in South Australia that used in-person interviewers. A few studies used postal questionnaires, most notably the Young Caregivers in the U.S. study, which asked questions (of parents) on young caring as part of a nationally representative omnibus

---

[20] Cree, V. E. (2003). Worries and problems of young carers: Issues for mental health. Child & Family Social Work, 8(4), 301-309.
Early, L., Cushway, D., & Cassidy, T. (2006). Perceived Stress in Young Carers: Development of a Measure. Journal Of Child And Family Studies, 15(2), 169-180. Fraser, E., & Pakenham, K. I. (2009). Resilience in children of parents with mental illness: Relations between mental health literacy, social connectedness and coping, and both adjustment and caregiving. Psychology, health & medicine, 14(5), 573-584.
Abrahams, K. and Aldridge, J. (2010) 'Who Cares for Me?': The Mental Well-Being of Young Carers in Manchester, Young Carers Research Group with Manchester Carers Forum and Child and Adolescent Mental Health Services (CAMHS), Manchester
[21] Banks, P., Cogan, N., Deeley, S., Hill, M., Riddell, S., & Tisdall, K. (2001). Seeing the invisible children and young people affected by disability. Disability & Society, 16(6), 797-814.
Siskowski, C. (2006). Young caregivers: Effect of family health situations on school performance. The Journal of School Nursing, 22(3), 163-169.
Nagl-Cupal, M., Daniel, M., Koller, M. M., & Mayer, H. (2014). Prevalence and effects of caregiving on children. Journal of Advanced Nursing
[22] Cass, B., Smith, C., Hill, T., Blaxland, M., & Hamilton, M. (2009). Young carers in Australia: understanding the advantages and disadvantages of their care giving. Australian Government, Department of Families Housing, Community Services and Indigenous affairs: Social Policy Research Paper no 38
[23] Cassidy, T., & Giles, M. (2013). Further exploration of the Young Carers Perceived Stress Scale: Identifying a benefit-finding dimension. British Journal Of Health Psychology, 18(3), 642-655.
[24] Burns, C., LeBlanc, T., Abernethy, A., & Currow, D. (2010). Young caregivers in the end-of-life setting: A population-based profile of an emerging group. Journal Of Palliative Medicine, 13(10), 1225-1235.

postal questionnaire[25]. Only a handful of smaller-scale studies (eg, Shifren and Kachorek, 2003[26]) used telephone interviews.

Studies that relied on existing young carers projects to provide data or distribute questionnaires are not suitable for estimating the prevalence of young caring; these studies, in addition to achieving low response rates, did not identify hidden carers. Likewise, school-based surveys were not suitable for identifying the prevalence of young caring across a large geographic area (ie, on a national level) as all existing school-based surveys relating to young carers have taken place on a relatively small scale.

After initial scoping of potential options, we selected school-based and in-home survey methodologies for detailed consideration. We concluded that an in-home survey is more effective than an in-school survey as it can offer:

- **The best coverage of 5 to 17 year olds without need for additional methodologies**. A school-based survey would require a separate approach for younger children who were not able to complete the survey themselves and bespoke sampling for the small number of 16 and 17 year olds undertaking apprenticeships with independent providers.

- **Lower design effects.** A random household survey offered the most representative sample for England with very low design effects due to the survey design. To make the survey workable for schools, an in-school survey must sample at least one class per school (c30 children) and to make the survey cost effective, given the effort involved in gaining response from schools, we considered it more realistic to plan for 60 children per school. However, the clustering of children within a school leads to design effects that must be balanced by a much larger achieved sample.

- **A higher response rate**. Although once a school agrees to take part in a survey the level of co-operation by pupils is often high, it is becoming increasingly difficult to persuade schools to participate in anything beyond mandatory data returns with a detrimental impact on the total response rate.

- **A lower risk of bias.** We know from the Longitudinal Study of Young People in England that young carers are more likely to miss school than pupils without

[25] National Alliance for Caregiving in Collaboration with the United Hospital Fund (2005) Young Caregivers in the U.S.: Report of Findings September 2005. Bethesda, MD: NAC.
[26] Shifren, K., & Kachorek, L. V. (2003). Does early caregiving matter? The effects on young caregivers' adult mental health. International Journal of Behavioral Development, 27(4), 338-346.

caring responsibilities. We would, therefore, under-represent some of the most vulnerable children if they do not attend on the day of an in-school survey.

Ideally, a random, large scale, nationally representative survey would be the ideal vehicle to investigating young caring but, given the pressure on content on UK Government National Statistics surveys, there would not be space to run a full module investigating the nature and impact of caring. Instead we recommended running the screening question to identify young carers on both the adult and young person interview on the Crime Survey for England and Wales (CSEW). This had the largest sample size and highest response rates of the surveys that we considered as eligible for this study and already carried a question on young caring that could be adapted.

For the questions on the nature and impact of caring we recommended using a quota sampled in-home Omnibus survey. Although the sampling methodology would make it unsuitable for precise estimates of prevalence at each age, the results can be reweighted to the distribution of young carers established in the 2011 Census and, eventually, the CSEW.

The Kantar TNS Face to Face Omnibus

The Kantar TNS face to face Omnibus uses random location sampling with the locations defined by a combination of Census Small Area Statistics and the Postcode Address File (PAF). There are 600 sample areas in Great Britain (south of the Caledonian Canal), each containing a similar size population. For each issued wave of the Omnibus, we sample up to 143 points after stratifying by Government Office Region and Social Grade. The sample is also checked to ensure urban/rural representativeness.

Interviewers are then given groups of Lower Layer Census Super Output Areas containing at least 125 addresses within which to achieve an adult sample of 15, 17 or 19 interviews in provincial areas, and 13, 15 or 17 in London depending on questionnaire length that wave. Each interview typically lasts 25 to 30 minutes on average, including a few minutes of core socio-demographic questions.

Whilst the age profile of respondents will depend on the sampled area, interviewers are set quotas to achieve target numbers of interviews according to gender, working status and, for women, presence of children in the household. This is designed to overcome bias towards those more likely to be at home. Interviewers must also leave at least three doors between each completed interview. These very tight controls result in a far more representative achieved sample than is typical on quota sample surveys.

Appendix E. QAS-99

QUESTION ASSESSMENT FRAMEWORK EVALUATION OF IDENTIFICATION OF YOUNG CARERS IDENTIFICATION QUESTIONS

Evaluation Criteria:

A. READING/INSTRUCTIONS – FROM INTERVIEWERS' POINT OF VIEW

B. CLARITY:

C. ASSUMPTIONS/KNOWLEDGE/MEMORY/TASK DIFFICULTY:

D. SENSITIVITY/BIAS:

E. RESPONSE CATEGORIES:

F: ORDER/CONTEXT:

G: (OPTIONAL – USE ONLY IF MIXED-MODE OR IF MIXED-MODE MAY APPLY IN FUTURE): MODE EFFECTS

H. OTHER: Are there any other problems not identified above?

Section	Question source	Question text	Review-er	Date
	Census, 2011 **Q14**	Do you look after, or give any help or support to family members, friends, neighbours or others because of either: - Long-term physical or mental ill-health/disability? Problems related to old age? Do not count anything you do as part of your paid employment • No • Yes, 1 - 19 hours a week • Yes, 20 - 49 hours a week • Yes, 50 or more hours a week		

A: READING/ INSTRUCTIONS	Having words separated by a slash is not ideal for interview administered interviews (eg,. CATI, CAWI) as it is difficult for an interviewer to read out.
B: CLARITY	The terms "help or support" could be interpreted in many different ways and, therefore, there is likely to be inconsistency in the answers given. There may be difficulty in assessing the number of hours per week and how a respondent should calucate this. For example if a respondent is living with an unwell relative, it may to be difficult to accurately assess how many hours of care they provide a week, if the care they provide is made up of lots of small acts, eg. helping up/down stairs; tying shoelaces; helping into/out of a vehicle. This could get even more difficult if the respondent interprets the question to include emotional support. Alternatively, if a respondent cares for a family member away from the household there may be travel time to and from their home and it would be unclear if this should be included. Whilst the question does specify "long-term physical or mental ill-health/ disability", no exact time period has been specified which may make it difficult for a respondent to decide what time period they should be considering when answering this question (for example care giving could be intermittent). Linked to this, it is unclear how a respondent should estimate the time they spend a week: is this the last week, or an average week over what period?
C: ASSUMPTIONS/ KNOWLEDGE/ MEMORY/TASK DIFFICULTY	There may be some problems with understanding around the phrase "long-term physical or mental ill-health/disability" for respondents depending on their age.

D: SENSITIVITY/ BIAS	Asking whether a respondent's family members are unwell will require some sensitivity as it may be a painful and/or uncomfortable topic. A respondent's answers may also be affected by whether family members are present in the room at the time of interview (eg, a respondent may be less likely to report caring if the person they care for is present).
E: RESPONSE CATEGORIES	The numeric range in the answer categories are very broad. For analysis purposes, there is a big difference between providing one hour of care a week and 19, and 20 hours and 49 hours.
F: ORDER/ CONTEXT	
G: MODE EFFECTS	
H: OTHER	The focus of this question is on all caring that the respondent may provide, both in the household and away from the household.

Section	Question source	Question text	Review-er	Date
	YCRG) Young Carer-QST-20 Q9-Q11	Q1 Do you live with a relative (parent, grandparent, brother, sister or other family member) who is ill or disabled? Q9 Do you provide any practical help in the house because of your relative's illness/disability (such as cooking, cleaning, helping with household chores)? Q9a If yes, what type of help do you provide? Q10 Do you provide any nursing-type help for your relative (such as helping to wash or dress them, give medication, helping them to move)? Q10a If yes, what type of help do you provide? Q11 Do you provide any emotional help to your relative (such as sitting with them, trying to make them laugh, cheer them up, talking to them about their problems)?	NM	03/10

A: READING/ INSTRUCTIONS	Having words separated by a slash is not ideal for interview administered interviews (eg, CATI, CAWI) as it is difficult for an interviewer to read out. Having words within brackets can also cause difficulties as it is not clear whether the interviewer should or should not read out this information.
B: CLARITY	The term "ill" could potentially be confusing for a respondent because the question does not indicate whether this is a short-term temporary illness (eg.. the flu) or a long-term illness. As "ill" appears with disabled it may be more likely that the respondent is thinking about longer term illnesses (as disability indicates permanence). The questions state "your relative". If a respondent lives with more than one household member with an illness or disability, it is unclear whether they answer about just one relative or all such relatives.

	The term "nursing-type" help in Q10 could potentially be difficult for a respondent to understand. In addition, although examples are given could there be some potential overlap between this and "practical" help – eg,. for a respondent helping someone to move may be seem to be a practical task. The term "emotional help" in Q11 could be potentially difficult for a respondent to understand and answer about. For example, many young people will have an emotional relationship with their parents, but at what point does it turn into emotional dependence (eg,. many children are likely to have these types of interactions with their parents). Additionally, young people may not always be aware of the emotional help they provide, and although examples are given, they may be less likely to report doing these things
C: ASSUMPTIONS/ KNOWLEDGE/ MEMORY/TASK DIFFICULTY	No time period has been specified, so it may be difficult for a respondent to know whether this refers to help they are currently providing, provided in the recent past or the frequency of the help.
D: SENSITIVITY/ BIAS	As previous questions evaluated. However, in addition, Q11 asks specifically about emotional help which may indicate mental illness with a family member, and mental health issues may be more even more sensitive than physical health problems and disabilities. Young people may be less likely to disclose this type of help.
E: RESPONSE CATEGORIES	
F: ORDER/ CONTEXT	
G: MODE EFFECTS	
H: OTHER	This question would not pick up help that a respondent may provide for a non-relative in the household; however, instances of this are likely to be very rare. These questions may also not pick up help that the respondent provides for the relative outside the help – such as shopping. Some young people may include this in Q9 as practical help, but some may not as this does not specifically take place in the household.

Section	Question source	Question text	Review-er	Date
	Crime Survey (CARER)	Some people your age may have to look after other people. This could be a brother or sister, a relative or someone else who is disabled or sick. Is there anyone like this who lives here with you that you have to look after on a regular basis? Yes - in this household No		

A: READING/ INSTRUCTIONS	
B: CLARITY	It is unclear whether a respondent should only include care they provide for someone who is disabled or sick. If a respondent for example has to look after their young siblings on a regular basis should they answer yes to this question?
C: ASSUMPTIONS/ KNOWLEDGE/ MEMORY/TASK DIFFICULTY	The instructions "brother or sister, a relative or someone else" may focus a respondent's mind too narrowly - for example, they may not include a parent, because whilst a parent is a relative the term "relative" may focus their mind on less close relatives such as grandparents. It may be difficult for all respondents to understand what a "regular basis" means.
D: SENSITIVITY/ BIAS	As previous question evaluated.
E: RESPONSE CATEGORIES	
F: ORDER/ CONTEXT	

G: MODE EFFECTS	
H: OTHER	The focus of this question is on care provided for someone who the respondent lives with. Therefore, it would not pick up any caring conducted for someone outside the household.

Section	Question source	Question text	Review-er	Date
	LSYPE2 Care	Some people your age have to provide regular help or support to people they live with who are physically or mentally ill, disabled or misusing drugs or alcohol. This could be a parent, brother, sister, a relative or someone else. Is there anyone like this who lives here with you that you have to look after on a regular basis?		

A: READING/ INSTRUCTIONS	
B: CLARITY	It may be difficult for all respondents to understand what a "regular basis" means. It may be difficult for all respondents to understand what "misusing drugs or alcohol" means.
C: ASSUMPTIONS/ KNOWLEDGE/ MEMORY/TASK DIFFICULTY	
D: SENSITIVITY/ BIAS	As per previous questions.
E: RESPONSE CATEGORIES	
F: ORDER/ CONTEXT	

G: MODE EFFECTS	
H: OTHER	The focus of this question is on care provided for someone who the respondent lives with. Therefore, it would not pick up any caring conducted for someone outside the household.

Section	Question name	Question text	Review-er	Date
	Survey of disability, ageing and carers. Carer Identification questions.	I'm now going to read you a list of everyday types of activities. Could you please tell me if anyone in [household] helps or supervises another member [household] who has a long-term health condition or disability, or who is elderly. We are interested in help that is ongoing or likely to be ongoing for at least six months. Does anyone in [household] help or supervise another member of the household with: - Moving about the house? - Getting in or out of a bed or chair? - Moving around places, away from the home? - Showing or bathing? - Getting dressed - for example doing up shoelaces, buttons or zips? - Eating meals - for example cutting up food? - Using the toilet or with managing a bladder or bowel problem? Still thinking about help that is ongoing or likely to be ongoing for at least six months. Does anyone in [household] help another member of [household] to communicate: - with people they do not know? - with family or friends? I would now like to ask you about any assistance given to people outside [this household/this unit]. We are interested in help that is ongoing or likely to be ongoing for at least six months. Do [you/anyone in the household] help or supervise someone living elsewhere who has a long-term health condition or disability, or is elderly, with everyday types of activities?		

		- Yes - No Who [do/does] [name] help with the [task/tasks] mentioned? [Do/Does [name] provide this help to [recipnamefirst] on a regular, unpaid, informal basis? [Do/Does] [name] provide [recipnamefirst] with continuous care or [do/does] [name] only need to provide care to [recipnamefirst] during periods or episodes when [recipyour/his/her] condition deteriorates? 1. Provides continuous care 2. Provides episodic care		

A: READING/ INSTRUCTIONS	These questions are asked of an adult household respondent, and there are some terms which may be difficult for a young person to understand. This include: "helps or supervises another member" "help that is ongoing or likely to be ongoing for at least six months" "managing a bladder or bowel problem" "with continuous care or [do/does] [name] only need to provide care to [recipnamefirst] during periods or episodes when [recipyour/his/her] condition deteriorates?" "1. Provides continuous care" "2. Provides episodic care"
B: CLARITY	Respondents may interpret "everyday types of activities" in different ways.

C: ASSUMPTIONS/ KNOWLEDGE/ MEMORY/TASK DIFFICULTY	
D: SENSITIVITY/ BIAS	As per previous questions.
E: RESPONSE CATEGORIES	
F: ORDER/ CONTEXT	
G: MODE EFFECTS	
H: OTHER	These identification questions will pick up both care in the household and care away from the household.

Section	Question name	Question text	Review-er	Date
	Young Caregivers in the US	Are there any children or young adults aged 8 to18 living in your household who provide unpaid help or care to any person who has an ongoing health problem or chronic illness, or who is elderly, frail, disabled or mentally ill. [As needed: The person who received help or case does no need to live with you]. Just to be sure we do not miss any of the ways in which an 8 to 18 year old may be helping someone, I am going to read a list. To save time, I will use the word "ill" to mean ongoing health problems, chronic illness and mental illness. Does anyone in your household ages 8 to 18 provide unpaid help for any person who is ill, disabled, elderly or frail? [Randomise] a. With household chores or meal preparation b. With dressing or feeding c. In taking medicine or communicating with doctors and nurses d. Keeping company or providing emotional support e. With shopping f. With paperwork, bill, or arranging outside services g. With moving around the house or getting around the community h. With bathing or using the bathroom		
A: READING/ INSTRUCTIONS	As part of the question text is an 'as needed' instructions, it will not always be read out by an interviewer. This could cause inconsistencies between respondents' answers.			

	These questions are asked of an adult household respondent, and if asked to a young person, there may be some terms which may be difficult to understand (depending on age). These include: "ongoing health problem or chronic illness, or who is elderly, frail, disabled or mentally ill" "communicating with doctors and nurses" "getting around the community".
B: CLARITY	The phrase "providing emotional support" may be interpreted in different ways by different respondents, especially as no examples of what this may include are given.
C: ASSUMPTIONS/ KNOWLEDGE/ MEMORY/TASK DIFFICULTY	
D: SENSITIVITY/ BIAS	As previous question comments.
E: RESPONSE CATEGORIES	
F: ORDER/ CONTEXT	
G: MODE EFFECTS	
H: OTHER	These identifications will pick up both care in the household and care away from the household (provided the 'as needed' part of the question text is read out).

Appendix F. Cognitive Testing

F.1 Methodology

The Kantar Public research team conducted face-to-face cognitive interviews with children aged 6 to 16, and with some of their parents. Interviews were conducted from 6 January to 16 January 2015. Children and their parents was sampled from a young carers support group and from Kantar Public's own survey sample sources where they had previously indicated some caring activities. Where possible, respondents were interviewed individually but, in some cases, it was more appropriate to conduct joint interviews with both the child and parent, or with two/three siblings.

The following questions were tested[27]:

- A single question about young caring: Two alternative questions were tested. These alternatives were drawn on the existing questions from the CSEW, LSYPE2 and the Census 2011. For each alternative, two versions were created: one to be asked directly to the child, and one to be asked to the parent to answer by proxy about their child.

- A short set of prevalence questions to measure young caring which could be placed on a national survey. These questions were drawn from previous survey tools and other surveys, and their aim was to estimate the prevalence of young caring with essential indicators of the type of caring done and the hours conducted each week. Two versions of these questions were created: one to be asked directly to the child, and one to the parent to answer by proxy about their child.

The aim of the cognitive testing was to explore understanding and interpretation of the questions. A combination of interviewer administered and self-completion methods were used for the administration of the questions, before reviewing each in detail with respondents. Interviews lasted between 15 to 30 minutes.

In total, interviews were conducted with 15 children and 7 parents. The findings and question recommendations are discussed in the next sections.

[27] The question texts are shown in the next section.

F.1 Single question about young caring

Option 1	
Child question wording	**Parent question wording**
Do you look after, or give any regular help or support to family members, friends, neighbours or others because of either: - Long-term physical or mental ill-health / disability? - Problems related to old age? - Misuse of drugs or alcohol? 1. Yes, in this household 2. Yes, outside this household 3. No 4. Don't know 5. Don't want to answer	Thinking of any children aged 5-17 in the household, [does/do] your child[ren] look after, or give any regular help or support to family members, friends, neighbours or others because of either: - Long-term physical or mental ill-health / disability? - Problems related to old age? - Misuse of drugs or alcohol? 1. Yes, in this household 2. Yes, outside this household 3. No 4. Don't know 5. Don't want to answer
Option 2	
Child question wording	**Parent question wording**
Some people your age have to provide regular help or support to people who are physically or mentally ill, disabled or misusing drugs or alcohol. This could be a parent, brother, sister, another relative or someone else. Is there anyone like this who you have to look after on a regular basis? This could include people who live with you and people who do not. 1. Yes – in this household 2. Yes – outside the household 3. No Don't know Don't want to answer	Some people have to provide regular help or support to people who are physically or mentally ill, disabled or misusing drugs or alcohol. This could be a parent, brother, sister, another relative or someone else. Thinking about any children aged 5-17 in the household, is there anyone like this who your [child/children] have to look after on a regular basis? This could include people who live with you and people who do not. 1. Yes – in this household 2. Yes – outside the household 3. No Don't know Don't want to answer

Feedback from parents

Generally, parents were able to understand and answer these questions, and the majority accurately reported that there was a young carer in the household. However, there were a couple of instances of confusion:

- One parent initially said no to this question (version 1), but then, after a couple of moments, answered 'yes'. This was because the help their son provided was with very small practical tasks (eg, helping to lift and carry items) and they had not initially been thinking about these things.

- For one parent, the question was confusing and slightly ambiguous due to the family circumstances. In the household, a household member had moved into a care home, so the child no longer provided care for them at home but at the care home instead. It was anticipated that the household member would return

home in the future, at which point, the household caring activities would resume.

Whilst parents were generally able to understand and answer these questions there were some variations in the interpretations of terms. For example, interpretations of the term 'regular' varied. These included:

- Being at least three times a week.
- Doing something quite a few times a day.
- Doing something five to seven times a week, something you would do most days.
- Doing something frequently, daily or at least several times a week.

In some interviews, parents were questioned about the use of the term 'ongoing' instead of regular:

- One parent described 'ongoing' as meaning 'currently', and described this as the sort of situation that, if you were receiving benefits for caring, you would need to advise if you stopped doing so.
- One parent described 'ongoing help' as being subtly different to regular help, and more focused around essential tasks that need to be on an ongoing basis (such as changing dressings). 'Regular help', however, focused their mind on individual, separate and potentially one-off tasks that they might do to help.

Other feedback/findings that arose were:

- For one parent, the terms 'looks after' and 'give support' in version 1 elicited very different feelings, reporting that 'looks after' made them think of someone with a disability and caring for them, whereas, 'give support' sounded like something more clinical.
- One parent reported that they felt the term 'misuse of drugs or alcohol' was quite intrusive and commented that they thought others might feel uncomfortable answering about this. They felt that children would understand what the question was asking, without the need to prompt them with particular conditions someone might have.
- One parent interpreted the term 'outside the household' as helping people outside of the house, rather than helping people who lived in a different household. Whilst this was only reported by one parent, it was a feeling that was echoed in some of the child interviews (discussed further below).

Three parents were asked which version of the question they preferred and why:

- One parent had a preference for the version 1 question. They felt the version 2 question was a little unclear in who it was trying to identify; as the first sentence did not state who the question was concerning. They reported having to re-read the question to understand who they should be answering about.

- One parent had a preference for the version 2 question, as they found version 1 confusing and had to re-read this several times.

- One parent did not have a preference for one version over the other. They felt they were both quite long and wordy, but acknowledged there were lots of specifics in both questions which needed to be included.

Feedback from children

Understanding and interpretation of the questions was much more varied amongst children, than amongst adults. Amongst the older children:

- One child (aged 15/16), answered yes to version 1 question. However, when probed, it was clear that they were just thinking about looking after their younger siblings in the household, which had nothing to do with their parent's disability. When the question was read out because it was relatively long and wordy, they seemed to purely focus on the term 'look after' at the start of the question, and did not remain engaged with the rest of the text. They, therefore, just thought about their younger siblings who they looked after.

- In another interview (aged 15/16), the respondent reported that the support they provided was for their parent who had to care full time for their grandparent. They helped out with chores and tasks around the house for because their parent's time was taken up with caring for the grandparent. They did not provide any direct care/support for their grandparent and, therefore, had some uncertainty about whether they should answer 'yes', or 'no' to either of these questions.

Amongst the younger children understanding was also mixed. Some children were asked to read the question themselves and the majority struggled to do this. Comprehension was far better when the question(s) were read out to them and the majority of the children had a grasp of what the question was asking. When asked to explain what they though it meant, responses included:

- Helping someone who had special needs (6, 8 and 11 year olds joint interview).

- Whether they look after anyone in their family (9 and 7 year olds joint interview).

- Thinking about help or support you might give to someone who is disabled or sick, so someone who is about to die or maybe someone who has had a stroke (joint 9 and 7 year olds interview).

- Understanding ‘help or support’ to mean ‘to make someone feel happy or good’.

However, in one interview (a joint interview with a 9 and a 10 year old) both children struggled when they were asked version 1 of the question, and did not understand the terms ‘regular, ‘help’ or ‘support’.

Similarly to the parents there was variation in the interpretation of the term ‘regular’:

- Tasks you might do every day, or at least twice a week (6, 8 and 11 year olds joint interview).

- Things you do some days (11 year old interview).

- Help you give everyday or the next day (7 and 9 year olds joint interview).

- Doing something a lot but not all the time (10 year old interview).

- Doing something some days (11 year old interview).

- Made the respondent think of school days only (15/16 year old interview).

Across both versions of the questions, the younger children (those aged 11 and under) were prompted about their understanding about ‘inside the household’ and ‘outside the household’. Interestingly, a significant proportion interpreted ‘inside the household’ to be about caring/help that someone does for someone whilst they are physically inside their house, and for ‘outside the household’ they were thinking about help that someone might provide whilst they are physically ‘outside’ the household (eg, at the park or at the shops).

Amongst one of the interviews with an older child (aged 15/16), they reported they understood the difference between inside and outside of the household. When probed about what ‘outside’ the household meant to them, they reported that if they saw someone struggle to get on or off a bus then he would help, but was not sure if this sort of help should count.

Recommendations

As mentioned in the discussion above, both questions contained elements that respondents interpreted inconsistently or differently from how they were intended. We do not recommend using the word 'regular' because of variation in interpretation. When alternatives were explored, although still with some difficulties, the word 'ongoing' generated more consistent interpretations among both children and parents as something that you have been doing and expect to carry on doing for the foreseeable future . We, therefore, recommend using this term instead.

In addition, we do not recommend using the term 'household', even if only in the answer codes, due to the confusion this caused for some respondents.

As many respondents were put off by the wordiness of the questions, and given that we want to offer greater clarity in the definition, we recommend the development of the second option which contains a statement and then a short question, rather than one long question. This is also the closest to the existing question minimising the change in wording between years. We suggest:

> *Some people your age provide help or support to people who are physically or mentally ill, disabled or misusing drugs or alcohol. This could be a parent, brother, sister, another relative or someone else.*
>
> *Is there anyone like this who you have to look after on an ongoing basis? This could include people who live with you and people who do not.*
>
> *1. Yes – someone I live with*
> *2. Yes – someone I do not live with*
> *3. No*

We would need to apply a similar adult question to identify children aged 5 to 9 (by proxy) and young people aged 16 or 17 directly (and by proxy). This will depend on whether ONS can make the questionnaire space available to DfE in the 2015/16 survey.

D.2 Prevalence questions

Question 1

Child question wording	Parent question wording
1. Is there anyone in this household who has a long-standing physical or mental illness or disability, or anyone who misuses drugs or alcohol? • Yes • No	1. Is there anyone in this household who has a long-standing physical or mental illness or disability, or anyone who misuses drugs or alcohol? • Yes • No

• Don't know • Don't want to answer	• Don't know • Don't want to answer

Generally, all parents appeared to understand and comprehend this question. However, there were some slight inconsistencies in the interpretation of 'long-standing'. For example, one parent considered it as something that had been going on for more than ten years, or since birth. Whereas another parent considered it more in terms of conditions which have a significant impact on someone's life. Interestingly, for this parent there was confusion as to whether or not they should include people with asthma here.

For one parent, the phrase 'misuses drugs or alcohol' caused some amusement as they reported taking a very large amount of medication each day for their condition, and joked whether you would consider that as misusing drugs.

The majority of children understood the question but there was some uncertainty amongst some of the younger children. For example, one of the 11 year-olds did not understand the term 'long-standing', however, when followed up, the term 'ongoing' seemed easier to understand.

In line with the parents, there were some differences in understanding and interpretation:

- Understanding of the question to be about things that do not fully go away (joint 8 and 11 year-olds interview).
- Thinking about the term long-standing in a 'future' focused way – thinking about how long the ailment would last, rather than 'past' focused, and not thinking about how long a condition had been going on for (joint 8 and 10 year old interview).
- Interpretation of the question to be asking about problems that exist for a long time, such as autism, disability or an addiction to drugs (10 year-old interview).
- Interpretation of the question to be asking whether there was anyone sick in the household (joint 7 and 9 year-old interview).
- Interpretation of 'longstanding' to be several years or more (15/16 year-old interview).
- One child included a household member with an injury in the question that took place around two years ago but was still having some impact on their life (15/16 year-old interview).

As noted earlier, these identification questions will not be asked directly to children under the aged of 10 (and will be collected via proxy from their parent).

Whilst there were some inconsistencies in the respondents' interpretation of 'long-standing', this is a very commonly used survey term and, on balance, we think it should remain unchanged.

In the cognitive testing, this question was asked after the 'single question' and, therefore, the definition of a household had been discussed before reaching this point. However, for the same reasons as discussed previously, we recommend changing the word 'household' and suggest the following wording is use:

> *Do you, or anyone who lives with you have a long-standing physical or mental illness or disability, or misuse drugs or alcohol?*
>
> 1. *Yes*
> 2. *No*
> 3. *Don't know*
> 4. *Don't want to answer*

Question 2

Child question wording	Parent question wording
If 1 = yes 2. And can I just check how many people are there in this household with these conditions? Numeric Don't know Don't want to answer	*If 1 = yes* 2. And can I just check how many people are there in this household with these conditions? Numeric Don't know Don't want to answer

Virtually all respondents answered this question without any difficulties. However, there was one respondent (aged 15/16) for whom this question caused some confusion as they themselves had a limiting condition as well as providing care for someone else with a limiting condition, and did not know whether they should include themselves or not.

We recommend amending the text to include a reference to the respondent themselves:

> *And can I just check, including yourself, how many people are there in this household with these conditions?*

Question 3

Child question wording	Parent question wording
If 1 = yes	*If 1 = yes*

3. And what is [their relationship/ the relationship of these people] to you?[28] *Multicode up to Q2 response* 1. Mother / Step mother 2. Father / Step father 3. Brother 4. Sister 5. Grandmother 6. Grandfather 7. Aunt 8. Uncle 9. Other relative (specify) 10. Other non-relative (specify) 11. Don't want to answer	3. And what is [their relationship/ the relationship of these people to you] to you?[29] *Multicode up to Q2 response* 1. Myself 2. Parent/ Husband / Wife 3. Mother / Step mother 4. Father / Step father 5. Daughter 6. Son 7. Brother 8. Sister 9. Grandmother 10. Grandfather 11. Aunt 12. Uncle 13. Other relative (specify) 14. Other non-relative (specify) 15. Don't want to answer

There were no difficulties with this question.

Whilst there were no difficulties associated with this question, we would recommend adding 'myself' into the allowable codes for the child questionnaire.

Question 4 and 5

Child question wording	**Parent question wording**
If 1 = yes 4. Do you provide any care for [TEXTFILL: this person/any of these people?][30] This could be: - practical help: such as cooking, cleaning, helping with household chores - nursing-type help: such as helping them to wash or to dress, give medication, helping them to move - emotional help: such as sitting with them, trying to make them laugh, cheer them up, talking to them about their problems 1. Yes 2. No 3. Don't know 4. Don't want to answer	*If 1 = yes* 4. Does [name of child][31] provide any care for [TEXTFILL: this person/any of these people?][32] This could be: - practical help: such as cooking, cleaning, helping with household chores - nursing-type help: such as helping them to wash or to dress, give medication, helping them to move - emotional help: such as sitting with them, trying to make them laugh, cheer them up, talking to them about their problems 1. Yes 2. No 3. Don't know 4. Don't want to answer

[28] Question repeated for number of people given at Q2.
[29] Question repeated for number of people given at Q2.
[30] Textfill based on number of people given at Q2.
[31] Child who will complete the child cognitive interview
[32] Textfill based on number of people given at Q2.

5. And what sort of care or help do you provide for them? CODE ALL THAT APPLY 1. Practical help: such as cooking, cleaning, helping with household chores 2. Nursing-type help: such as helping them to wash or to dress, give medication, helping them to move 3. Emotional help: such as sitting with them, trying to make them laugh, cheer them up, talking to them about their problems 4. Other care or help (Specify) 5. Don't know 6. Don't want to answer	5. And what sort of care or help does [name of child] provide for them? CODE ALL THAT APPLY 1. Practical help: such as cooking, cleaning, helping with household chores 2. Nursing-type help: such as helping them to wash or to dress, give medication, helping them to move 3. Emotional help: such as sitting with them, trying to make them laugh, cheer them up, talking to them about their problems 4. Other care or help (Specify) 5. Don't know 6. Don't want to answer

Parents generally appeared to understand and answer this question easily. For many, the example of care were not necessary, with some jumping in and answering 'yes' before the examples were read out. However, for others, they were helpful in helping them to think about all the things their child might do.

Among many children the term 'care' was not meaningful enough on its own for them to be able to answer this question, with the second part of the question giving examples being essential to their understanding. This appeared to be for a variety of reasons, including children who did not really fully understand the term 'care' and others who did understand the term, but di not necessarily categorise what they did as caring.

When the examples of care were read out, whilst the older children understood the terms 'practical help', 'nursing type help', 'emotional type' help, the younger children generally struggled to understand these terms. For them, the specific examples were necessary for them to think about the care and support they provided. Interestingly, amongst the older children there were different understandings and thinking about 'emotional help'. One older child (aged 15/16) reported that the care they provided for someone was purely emotional (sitting with them helping to cheer them up), whereas another older child (aged 15/16), when probed on this question, had not previously been considering any of the emotional support they provided as care.

When all respondents were prompted with the list of activities, some noted other things they did/their children did to provide care and support in the home. Examples included:

- Helping with homework and education for their sibling with autism, in addition to helping them to get there things ready for school in the morning, and giving them instructions as to how to do things. They also considered playing games with them as care.

- One child reported carrying out many different tasks for their mother (such as cooking and cleaning), but this was because their brother had autism, and their mother had to spend a lot of time caring for their brother ,so they needed help around the house with a lot of chores.

- Some respondents reported help with shopping and running errands.

- Some respondents reported help with lifting and carrying things, picking things up.

- One respondent reported help with the decorating.

As noted earlier, we will not be asking these questions directly to children under the aged of 10. We, therefore, recommend that question 4 is retained in its current format. However, in the description of 'emotional help', we would recommend removing the term 'trying to make them laugh' as this is quite repetitious of 'cheering them up'. We would also suggest including 'Going to the shops' as a further example of practical help, as errand running and helping with shopping was mentioned by some respondents.

Do you provide any care for [TEXTFILL: this person/any of these people?] This could be:

- *Practical help: such as cooking, cleaning, helping with household chores, going to the shops;*

- *nursing-type help: such as helping them to wash or to dress, give medication, helping them to move;*

- *emotional help: such as sitting with them, cheering them up, talking to them about their problems.*

Question 5 collects desirable information, but we do not feel it is essential to identifying prevalence if space is very limited. If this question was taken forward on any survey we would recommend the same changes in line with those recommended for question 4 are made.

Question 6

Child question wording	Parent question wording
If 4 = yes 6. And approximately, how long have you been providing care for [TEXTFILL: this person/ these people?][33]	*If 4 = yes*

[33] Textfill based on number of people given at Q2.

1. Less than 3 months 2. 3 months but less than a year 3. 1 year but less than 2 years 4. 2 years or more 5. Don't know 6. Don't want to answer	6. And approximately how long has [name of child] been providing care for [TEXTFILL: this person/ these people?][34] 1. Less than 3 months 2. 3 months but less than a year 3. 1 year but less than 2 years 4. 2 years or more 5. Don't know 6. Don't want to answer

Whilst the majority of parents and children could provide an answer to this question, they generally did not answer with the answer codes given. Many struggled to give an exact date, and reported that they/their child had done it all their life and, therefore, could not pin point exactly when the care started. Where parents and children did give specific start dates they generally answered by giving the age they/their child was when they first started providing the care (eg, 'since I was 10'). For all interviewed it was longer than two years.

We would recommend potentially removing this question from the short set of identification questions. Whilst this information is helpful and would provide interesting information to enhance the prevalence figure, we do not feel this is essential information. Additionally, as a number of respondents had difficulties in providing an exact date when the caring started, we would anticipate that the question is unlikely to yield very accurate information.

Question 7

Child question wording	Parent question wording
If 4 = yes 7. Approximately, how many hours a week do you spend [TEXTFILL: in total][35] helping to look after or care for [TEXTFILL: this person / these people][36] at home? INTERVIEWER: IF THE PERSON DOES NOT KNOW, PLEASE ASK FOR THEIR BEST ESTIMATE. Numeric	*If 4 = yes* 7. Approximately, how many hours a week does [name of child] spend [TEXTFILL: in total][37] helping to look after or care for [TEXTFILL: this person / these people][38] at home? INTERVIEWER: IF THE PERSON DOES NOT KNOW, PLEASE ASK FOR THEIR BEST ESTIMATE. Numeric

[34] Textfill based on number of people given at Q2.
[35] Textfill based on number of people given at Q2.
[36] Textfill based on number of people given at Q2.
[37] Textfill based on number of people given at Q2.
[38] Textfill based on number of people given at Q2.

Don't know Don't want to answer	Don't know Don't want to answer

This question was problematic and difficult to answer by the majority of respondents (both parents and children):

- For many, the care they provided was made up of very small tasks (such as picking something up for a parent if they couldn't lift it) and it was, therefore, hard for them to think about total time all these very small things take up.

- For some respondents, whilst tasks may be slightly larger (eg, cooking dinner, cleaning the bedrooms), many respondents still struggled to think through all the tasks and come up with an estimate.

- Some respondents reported that they care they provided varied so it was hard to estimate the average time spent. The main variations were between weekdays and weekends but, for some, it was much more sporadic (for example, one child reported caring for their cousin, who stayed with them for differing lengths of time, sometimes for a whole month at time, sometimes just for a week at a time. Another child reported that it varied between term time and school holidays).

The majority of respondents did eventually manage to give an estimate however, this tended to be after a considerable amount of probing and prompting the respondent to try to split up their day and think about what they (for example, before going to school, after getting home from school). For one parent, a discrepancy was noted with an earlier answer. They reported, spontaneously, at the start of the interview (without any questioning or prompting) that their son provided about 20 hours a week or care. However, later on in the interview when Q7 was asked, when they calculated a daily number of hours, and totalled this per week, it totalled nearly 40 hours.

Interestingly, for one child (aged 10), this question did cause some difficulties because they reported that they did not really look after their cousin, but that they just 'helped out'.

Due the range of problems that emerged, we do not recommend including this question in the prevalence questionnaire in its current format. We recommend that, if an estimate of hours is necessary to capture, the question should be broken down into an estimate of hours on the following types of days:

On a typical school day

On a typical day at the weekend or school holiday

For both questions we recommend allowing the option of 'No typical day', for those who still struggle to answer this.

Question 8

Child question wording	Parent question wording
If 4 = yes 8. Has caring for [this person/ this people][39] affected the amount of time you have for yourself, for example, going to school, doing homework, spending time with friends, hobbies? 1. Yes 2. No 3. Don't know 4. Don't want to answer	*If 4 = yes* 8. Has caring for [this person/ this people][40] affected the amount of time you think [name of child] has for themselves, for example, going to school, doing homework, spending time with friends, hobbies? 1. Yes 2. No 3. Don't know 4. Don't want to answer

Generally, this question worked well, with all parents and the majority of children understanding and easily answering this question. One parent and child reported feeling a little uncomfortable answering this but thought it was important to ask.

When probed about the term 'affected', respondents interpreted this as:

- Bothering you and stopping you from doing what you want to do (11 year-old interview).
- When something affects what you are doing/takes time away from what you are doing (joint 8 and 9 year-old interview).
- Being unable to cope with the complexities of the situation and not able to do general children's 'stuff' (parent interview).
- An inability for a child to use their free time because it was being taken up by helping out and caring (parent interview).
- Impacted on in a negative way. To take time away from the things they would like to be doing (parent interview).

Two parents reported that they thought this question sounded quite negative, and suggested a detrimental effect. Interestingly, a similar concept emerged during one of the joint child interviews (with a 6, 8 and 11 year old). They answered 'no' here, that it didn't

[39] Textfill based on number of people given at Q2.
[40] Textfill based on number of people given at Q2.

really affect their life (despite at the previous question reported a high number of caring hours). This was because they did not really see it as impacting on their life - it was just part of their life and they were happy to do it, and happy to put their brother first.

One parent reported that the examples did not fully cover the impacts caring can have someone's life, they reported that there could be important indirect impacts, for example, tiredness and stress, which may then have a knock on effect on other things such as school or work.

We would recommend retaining this question in its current format. Whilst a minority of respondents reported that this question had a slightly negative feel to it, it will be difficult to get away from this as the question is aiming to record any potential impact on the child. Although not required to estimate prevalence, it could be used to give an indicative measure of impact, which would add and enhance to the definition.

Question 9

Child question wording	Parent question wording
Ask all 9. And now thinking about people outside of the household. Do you provide any regular or ongoing care for anyone outside of the household with a long-standing physical or mental illness or disability, or anyone who misuses drugs or alcohol? For example, a family member, friend or neighbour. 1. Yes 2. No 3. Don't know 4. Don't want to answer	*Ask all* 9. And now thinking about people outside of the household. Does [name of child] provide any regular or ongoing care for anyone outside of the household with a long-standing physical or mental illness or disability, or anyone who misuses drugs or alcohol? For example, a family member, friend or neighbour. 1. Yes 2. No 3. Don't know 4. Don't want to answer

Generally, this question seemed to be understood and the majority of people answered it easily. Respondents did not struggle here with the term 'household'. However, this is because the definition would have already been discussed at the earlier questions in the cognitive testing.

In the cognitive testing, two children reported caring for someone outside the household. One of these children reported that a household member had moved into a care home, so they no longer provided care for them at home but, instead, at the care home. As mentioned earlier in the report, there was some confusion by the respondent as to whether they should include their caring as inside or outside of the household as the distinction for them was not clear cut. The advantage of having two sets so questions

(where both is collected) is that this information will definitely be captured irrespective of how the child/parent thinks about it.

In the cognitive testing, the definition of a household had already been discussed before reaching this question. However, for the same reasons as discussed previously we recommend changing the word 'household'. Similarly, we recommend that 'ongoing' care is sufficient for the definition and prevents respondents ruling themselves out because it is not 'regular enough'. The recommended wording would therefore be:

> *And now thinking about people who do not live with you. Do you provide any ongoing care for anyone who does not live with you with a long-standing physical or mental illness or disability, or anyone who misuses drugs* or alcohol? *For example, a family member, friend or neighbour.*

Questions 10 – 15

Child question wording	Parent question wording
If 9 = yes 10. And how many people do you provide care for outside of the household? Numeric Don't know Don't want to answer *If 9 = yes* 11. And what is [their relationship/ the relationship of these people to you] to you?[41] *Multicode up to Q10 response* 1. Mother / Step mother 2. Father / Step father 3. Brother 4. Sister 5. Grandmother 6. Grandfather 7. Aunt 8. Uncle 9. Other relative (specify) 10. Other non-relative (specify) 11. Don't want to answer *If 9 = yes* 12. And what sort of care or help do you provide for them? CODE ALL THAT APPLY 1. Practical help: such as cooking, cleaning, helping with household chores 2. Nursing-type help: such as helping them to wash or to dress, give medication, helping them to move	*If 9 = yes* 10. And how many people does [name of child] provide care for outside of the household? Numeric Don't know Don't want to answer *If 9 = yes* 11. And what is [their relationship/ the relationship of these people to you][44] to you?[45] *Multicode up to Q10 response* 1. Myself 2. Parent/ Husband / Wife 3. Mother / Step mother 4. Father / Step father 5. Daughter 6. Son 7. Brother 8. Sister 9. Grandmother 10. Grandfather 11. Aunt 12. Uncle 13. Other relative (specify) 14. Other non-relative (specify) 15. Don't want to answer *If 9 = yes* 12. And what sort of care or help do [name of child] provide for them? CODE ALL THAT APPLY 1. Practical help: such as cooking, cleaning, helping with household chores

[41] Question repeated for number of people given at Q10.
[44] Question repeated for number of people given at Q10.
[45] Question repeated for number of people given at Q10.

3. Emotional help: such as sitting with them, trying to make them laugh, cheer them up, talking to them about their problems 4. Other care or help (Specify) 5. Don't know 6. Don't want to answer *If 9 = yes* 13. And approximately how long have you been providing care for [TEXTFILL: this person/ these people?][42] 1. Less than 3 months 2. 3 months but less than a year 3. 1 year but less than 2 years 4. 2 years or more 5. Don't know 6. Don't want to answer *If 9 = yes* 14. Approximately, how many hours a week do you spend [TEXTFILL: in total] helping to look after or care for [TEXTFILL: this person / these people]? INTERVIEWER: IF THE PERSON DOES NOT KNOW, PLEASE ASK FOR THEIR BEST ESTIMATE. Numeric Don't know Don't want to answer *If 9 = yes* 15. Has caring for your [this person/ this people][43] affected the amount of time you have for yourself, for example, going to school, doing homework, spending time with friends, hobbies? 1. Yes	2. Nursing-type help: such as helping them to wash or to dress, give medication, helping them to move 3. Emotional help: such as sitting with them, trying to make them laugh, cheer them up, talking to them about their problems 4. Other care or help (Specify) 5. Don't know 6. Don't want to answer *If 9 = yes* 13. And approximately how long has [name of child] been providing care for [TEXTFILL: this person/ these people?][46] 1. Less than 3 months 2. 3 months but less than a year 3. 1 year but less than 2 years 4. 2 years or more 5. Don't know 6. Don't want to answer *If 9 = yes* 14. Approximately, how many hours a week does [name of child] spend [TEXTFILL: in total] helping to look after or care for [TEXTFILL: this person / these people][47]? INTERVIEWER: IF THE PERSON DOES NOT KNOW, PLEASE ASK FOR THEIR BEST ESTIMATE. Numeric Don't know Don't want to answer *If 9 = yes* 15. Has caring for your [this person/ this people][48] affected the amount of time you

[42] Textfill based on number of people given at Q10.
[43] Textfill based on number of people given at Q10.
[46] Textfill based on number of people given at Q10.
[47] Textfill based on number of people given at Q10.
[48] Textfill based on number of people given at Q10.

2. No 3. Don't know 4. Don't want to answer	think [name of child] has for themselves, for example, going to school, doing homework, spending time with friends, hobbies? 1. Yes 2. No 3. Don't know 4. Don't want to answer

For the cases where caring outside the household was identified, we then repeated the same questions regarding the type and amount of care given (questions 10 to 15 shown above).

As mentioned with question 9, there were two children who reported caring outside of the home and, therefore, details of their caring activities were established at these questions.

We recommend that, if space permits, these questions should be retained as they collect interesting information about caring responsibilities for people who are not resident in the household. However, we would recommend the same changes as suggested for questions 2 to 8 (the equivalent set capturing details of caring in the household).

Appendix G. Final Questionnaire – Young Carers & Comparison survey

C:\CFQ\RTFS\CARB603.RTF

Introduction

Question 199

Multiple answers allowed
Question only asked, if [RAN 1]
1102L100

Dummy Question for filter

1 ❑ F1 = All Adults aged 18+ in GB
2 ❑ F2 = All parents of 5-17 year old (living in the household) or aged 16 or 17 in GB Q1\1 or QUOTA AGE\16 or 17
3 ❑ F3 = All parents of 5-17 year old (living in the household) in GB Q1\1
4 ❑ F4 = All young adults aged 16 or 17
5 ❑ F5 = All parents of carers Q3A\1,2
6 ❑ F6 = All parents of carers of someone in the household Q3A\1
7 ❑ F7 = All parents of carers of someone outside the household Q3A\2
8 ❑ F8 = All parents of carers whose child receive support Q12\NOT N or DK
9 ❑ F9 = All whose patient receives support Q14\NOT N or DK
10 ❑ F10 = All carers aged 11-17 in GB DUMMY QUESTION B\1-7
11 ❑ F11 = All carers aged 11-17 who care for someone in the household Q17\1
12 ❑ F12 = All carers aged 11-17 who care for someone outside the household Q17\2
13 ❑ F13 = All carers aged 11-17 who receive support Q27\NOT N or DK
20 ❑ F20 = All parents of carers agreeing to be interviewed QB\1
21 ❑ F21 = All parents of carers agreeing to be interviewed and child agreeing QB\1 AND QC\1
22 ❑ F22 = All parents of carers Q3A\1,2 AND Q4A\ 11-17
23 ❑ F23 All carers aged 11-17 who care for someone Q17\1,2
30 ❑ F30 = All parents of 5-17 year old (living in the household) and none are young carers in GB Q3A\3
31 ❑ F31 : NEW Q4A\I said age 11-17 (codes 7-13) or the respondent is aged 16-17 and a non carer(Q3A,3). OR RESPONDENT IS AGED 16 OR 17 AND Q17\3

Question 9295

Minimum 16
Maximum 98
3428L2

Exec check: Age?

Question 10

Question only asked, if [FILTER[1] = 1]
1202L2

Q.1 Are you the parent of a 5 to 17 year old that lives in this household with you?

1 ❑ Yes
2 ❑ No

Question 20

Question only asked, if [FILTER[2] = 1]
1204L2

Q.2 Is there anyone in this household who has a long-standing physical or mental illness or disability, or anyone who misuses drugs or alcohol? This includes problems related to old age.

1 ❑ Yes
2 ❑ No

Question 31

Multiple answers allowed
Answers will be inverted randomly
Question only asked, if [FILTER[3] = 1]
1206L100

SHOW SCREEN-MULTI CHOICE
Q.3A Some children and young people provide help or support to people who are physically or mentally ill, disabled or misusing drugs or alcohol. This includes problems related to old age.
This could be a parent, brother, sister, another relative or someone else. Is there anyone aged 5 to 17 in this household who provides this type of care on an ongoing basis? This could include for people who live with you and people who do not.

1 ❑ Yes - for someone we live with in the household
2 ❑ Yes - for someone we do not live with outside the household
3 ❑ No

Question 41

Multiple answers allowed
Question only asked, if [FILTER[5] = 1]
1406L100

SHOW SCREEN-MULTI CHOICE
Q.4A And what is\are the age(s) of the child(ren) who provide that care?

1 ❑ 5 years old
2 ❑ 6 years old
3 ❑ 7 years old
4 ❑ 8 years old
5 ❑ 9 years old
6 ❑ 10 years old
7 ❑ 11 years old
8 ❑ 12 years old
9 ❑ 13 years old
10 ❑ 14 years old
11 ❑ 15 years old
12 ❑ 16 years old
13 ❑ 17 years old

Continue at question 7010_1
Continue at question 7010_2
Continue at question 7010_3
Continue at question 7010_4
Continue at question 7010_5
Continue at question 7010_6
If [cntQ4a = 0] otherwise continue at question 7011

Question 42

Multiple answers allowed
Question only asked, if [FILTER[5] = 1]
1546L100

Q.4B And what is the name of the <?>?

Question 51

Multiple answers allowed
Answers will be inverted randomly
Open ended answer is written as a bitmap
Question only asked, if [FILTER[6] = 1]
1646L100

SHOW SCREEN-MULTI CHOICE
Q.5A And who do they provide care for in the household?

1 ❑ Their mother
2 ❑ Their father
3 ❑ A brother or sister
4 ❑ A grandparent
5 ❑ Another relative
6 ❑ Another non relative

Question 52

Multiple answers allowed
Answers will be inverted randomly
Open ended answer is written as a bitmap
Question only asked, if [FILTER[7] = 1]
1746L100

SHOW SCREEN-MULTI CHOICE
Q.5B And who do they provide care for that they do not live with, outside the household?

1 ❑ Their mother
2 ❑ Their father
3 ❑ A brother or sister
4 ❑ A grandparent
5 ❑ Another relative
6 ❑ Another non relative

Question 61

Multiple answers allowed
Answers will be inverted randomly
Open ended answer is written as a bitmap
User defined button : 98 "DK"
User defined button : 99 "Prefer not to say"
Question only asked, if [FILTER[6] = 1]
1846L100

SHOW SCREEN-MULTI CHOICE
Q.6A What sort of care or help does <Question 42> provide for them in the household?

1 ❑ Practical help : such as cooking, cleaning, shopping, doing paperwork, helping with household chores
2 ❑ Nursing-type help : such as helping them to wash or to dress, give medication, helping them to move
3 ❑ Emotional help : such as sitting with them, trying to cheer them up, talking to them about their problems
4 ❑ Other type of care

Question 62

Multiple answers allowed
Answers will be inverted randomly
Open ended answer is written as a bitmap
User defined button : 98 "DK"
User defined button : 99 "Prefer not to say"
Question only asked, if [FILTER[7] = 1]
1946L100

SHOW SCREEN-MULTI CHOICE
Q.6B What sort of care or help does <Question 42> provide for them outside the household?

1 ❑ Practical help: such as cooking, cleaning, shopping, doing paperwork, helping with household chores
2 ❑ Nursing-type help : such as helping them to wash or to dress, give medication, helping them to move
3 ❑ Emotional help : such as sitting with them, trying to cheer them up, talking to them about their problems
4 ❑ Other type of care

Question 770

Question only asked, if [FILTER[5] = 1]

Q.7 Thinking about <Question 42>’s time at school or college, how much would you agree or disagree with the following statements?

Question 70_1

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2048L2

SHOW SCREEN AND READ OUT STATEMENT
His\her grades are better than average

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 70_2

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2052L2

SHOW SCREEN AND READ OUT STATEMENT
His\her attendance is better than average

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 70_3

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2056L2

SHOW SCREEN AND READ OUT STATEMENT
He\she enjoys going to school or college

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 70_4

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2060L2

SHOW SCREEN AND READ OUT STATEMENT
I think he\she will leave school or college feeling proud of his\her achievements

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 70_5

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2064L2

SHOW SCREEN AND READ OUT STATEMENT
He\she gets into a lot of trouble

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 70_6

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2068L2

SHOW SCREEN AND READ OUT STATEMENT
He\she has trouble making friends

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 70_7

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2072L2

SHOW SCREEN AND READ OUT STATEMENT
He\she gets involved with a lot of after school or college activities

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 70_8

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2076L2

SHOW SCREEN AND READ OUT STATEMENT
He\she often hands his\her homework in late

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 70_9

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2080L2

SHOW SCREEN AND READ OUT STATEMENT
He\she finds it hard to concentrate in lessons

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 70_10

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2084L2

SHOW SCREEN AND READ OUT STATEMENT
He\she is being bullied at school or college

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 780

Question only asked, if [FILTER[5] = 1]

Q.8 Here is a list of things that people do to help around the house. Thinking of the last month, please say which of these you think <Question 42> has done a lot, some of the time, a little or not at all?

Question 80_1

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2118L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Cleaned his\her bedroom

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 80_2

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2122L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Cleaned rooms other than bedroom

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 80_3

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2126L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Washed up dishes or loaded\unloaded the dishwasher

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 80_4

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2130L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Gone to the shops to buy food

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 80_5

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2134L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Helped prepare or cook meals

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 80_6

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2138L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Helped with decorating or DIY

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 80_7

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2142L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Helped with lifting or carrying heavy things

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 80_8

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2146L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Helped with financial matters like dealing with bills, collecting benefits, going to the bank

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 80_9

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2150L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Worked part-time to help bring money in

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 80_10

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2154L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Interpreted or signed for someone he\she lives with

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 80_11

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2158L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Kept someone in the family company if they can't go out much

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 80_12

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2162L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Taken brothers or sisters to school

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 80_13

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2166L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Looked after brothers or sisters whilst another adult is nearby

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 80_14

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2170L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Looked after brothers or sisters on his\her own

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 80_15

Answers will be inverted randomly
Question only asked, if [FILTER[5] = 1]
2174L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 42> has ...
Provided nursing-type help for someone he\she lives with

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 90

Answers will be displayed in random order
Question only asked, if [FILTER[5] = 1]

SHOW SCREEN
Q.9 Thinking back over the last year, how often would you say <Question 42> has...?
Never A few times 1 or 2 times a month 1 or 2 times a fortnight More than once a week ...

Question 101

Minimum 0
Maximum 24
Question only asked, if [FILTER[5] = 1]
2279L2

Q.10A Approximately, how many hours does <Question 42> spend on a typical school or college day helping to care for this person\these people?

Question 102

Minimum 0
Maximum 24
Question only asked, if [FILTER[5] = 1]
2281L2

Q.10B Approximately, how many hours does <Question 42> spend on a typical day at the weekend or school\college holiday helping to care for this person\these people?

Question 110

User defined button : 98 "DK"
Question only asked, if [FILTER[5] = 1]
2283L2

Q.11 Has <Question 42> received an assessment of their needs by the Local Authority separate from the person they care for?
The Local Authority could be the council or a local government agency.

1 ❑ Yes
2 ❑ No

Question 120

Multiple answers allowed
Answers will be inverted randomly
User defined button : 98 "DK"
User defined button : 99 "N"
Question only asked, if [FILTER[5] = 1]
2285L100

SHOW SCREEN-MULTI CHOICE
Q.12 Does <Question 42> receive support for themselves in their caring role from any of the following?

1 ❑ Social services
2 ❑ Health services
3 ❑ School\College
4 ❑ young carers' project
5 ❑ A charity (other than a young carer's project)
6 ❑ Someone else

Question 130

Answers will be inverted randomly
Answer categories mentioned in question 120 will be displayed
Question only asked, if [FILTER[8] = 1]

SHOW SCREEN
Q.13 Thinking of the support that <Question 42> receives, how much do you feel each type of support meets <Question 42>'s needs?
Fully meets his\her needs Partly meets his\her needs Does not meet his\her needs at all Don't know

Question 140

Multiple answers allowed
Answers will be inverted randomly
User defined button : 98 "DK"
User defined button : 99 "will not be displayed"
Question only asked, if [FILTER[5] = 1]
2391L100

SHOW SCREEN-MULTI CHOICE
Q.14 Does the person they care for receive support from any of the following?

1 ❑ Social services
2 ❑ Health services
3 ❑ A charity
4 ❑ Someone else

Question 150

Answers will be inverted randomly
Answer categories mentioned in question 140 will be displayed
Question only asked, if [FILTER[9] = 1]

SHOW SCREEN
Q.15 Thinking of the support that the cared for person receives from these sources, how much do you feel each type of support meets his\her needs?
Fully meets his\her needs Partly meets his\her needs Does not meet his\her needs at all Don't know

Question 160

Answers will be inverted randomly
User defined button : 98 "DK"
User defined button : 99 "Prefer not to say"
Question only asked, if [FILTER[5] = 1]
2495L2

SHOW SCREEN
Q.16 How would you say <Question 42>'s health is in general?

1 ❑ Very Good
2 ❑ Good
3 ❑ Bad
4 ❑ Very Bad

Question 1000

Open ended answer is written as a bitmap
User defined button : 96 "R"
Question only asked, if [FILTER[5] = 1]
2497L2

SHOW SCREEN
Q.A What is <Question 42>'s ethnic group?
(IF NECESSARY: By this I mean your cultural background)
*HEADING A. White

1 ❑ White British
2 ❑ White Irish
3 ❑ Any other white background
*HEADING B. Mixed
4 ❑ White & Black Caribbean
5 ❑ White & Black African
6 ❑ White & Asian
7 ❑ Any other mixed background
*HEADING E. Chinese or other Ethnic group
15 ❑ Chinese
16 ❑ Any other
*HEADING C. Asian or Asian British
8 ❑ Indian
9 ❑ Pakistani
10 ❑ Bangladeshi
11 ❑ Any other Asian background
*HEADING D. Black or Black British
12 ❑ Caribbean
13 ❑ African
14 ❑ Any other Black background

Question 2000

Answers will be inverted randomly
Open ended answer is written as a bitmap
Question only asked, if [FILTER[22] = 1]
2499L2

SHOW SCREEN
Q.B We would like to ask <Question 42> a few questions about their role in the family. Would that be okay and is he\she available now?

1 ❑ Agree to child be interviewed and child is available INTERVIEWER COLLECT SIGNATURE
2 ❑ Agree to child be interviewed and child is not available
3 ❑ Disagree - would prefer child not to be interviewed

If [Q2000 , 2 , 3] go to end of questionnaire

Question 1001

Question only asked, if [FILTER[20] = 1]

INTERVIEWER: NOW PLEASE ASK FOR THE PARENT\GUARDIAN TO ASK THE CHILD TO COME AND BE INTERVIEWED.

Question 731

Answers will be inverted randomly
Question only asked, if [FILTER[20] = 1]
2501L2

SHOW SCREEN
Q.C Can I ask for the child's permission to be interviewed?

1 ❑ Child Agreed
2 ❑ Child Refused

If [Q731 , 2] go to end of questionnaire

Question 3000

Question only asked, if [RAN 1]
2503L2

DUMMY QUESTION B
SCRIPTERS THIS IS TAKEN FROM Q4B PRIORITY ORDER AND IF PARENT AND CHILD GIVES PERMISSION TO BE INTERVIEWED

1 ❑ Carers aged 11 agreeing to be interviewed Q4B\11 AND QB\1 AND QC\1
2 ❑ Carers aged 12 agreeing to be interviewed Q4B\12 AND QB\1 AND QC\1
3 ❑ Carers aged 13 agreeing to be interviewed Q4B\13 AND QB\1 AND QC\1
4 ❑ Carers aged 14 agreeing to be interviewed Q4B\14 AND QB\1 AND QC\1
5 ❑ Carers aged 15 agreeing to be interviewed Q4B\15 AND QB\1 AND QC\1
6 ❑ Carers aged 16 agreeing to be interviewed [Q4B\16 AND QB\1 AND QC\1] OR [RESPONDENT AGED 16]
7 ❑ Carers aged 17 agreeing to be interviewed [Q4B\17 AND QB\1 AND QC\1] OR [RESPONDENT AGED 17]

Question 170

Multiple answers allowed
Answers will be inverted randomly
Question only asked, if [FILTER[10] = 1]
2505L100

SHOW SCREEN-MULTI CHOICE
Q.17 Some people your age provide help or support to people who are physically or mentally ill, disabled or misusing drugs or alcohol. This includes problems related to old age. This could be a parent, brother, sister, another relative or someone else. Do you provide this type of care on an ongoing basis? This could include for people who live with you and people who do not.

1 ❑ Yes - for someone I live with in the household
2 ❑ Yes - for someone I do not live with outside the household
3 ❑ No

Question 181

Multiple answers allowed
Answers will be inverted randomly
Open ended answer is written as a bitmap
Question only asked, if [FILTER[11] = 1]
2605L100

SHOW SCREEN-MULTI CHOICE
Q.18A And who do you provide care for in the household? Is it...

1 ❑ Mother
2 ❑ Father
3 ❑ A brother or sister
4 ❑ A grandparent
96 ❑ Another relative
97 ❑ Another non relative

Question 182

Multiple answers allowed
Answers will be inverted randomly
Open ended answer is written as a bitmap
Question only asked, if [FILTER[12] = 1]
2705L100

SHOW SCREEN-MULTI CHOICE
Q.18B And who do you provide care for outside the household? Is it...

1 ❑ Mother
2 ❑ Father
3 ❑ A brother or sister
4 ❑ A grandparent
96 ❑ Another relative
97 ❑ Another non relative

Question 191

Multiple answers allowed
Answers will be inverted randomly
Open ended answer is written as a bitmap
User defined button : 98 "DK"
User defined button : 99 "Prefer not to say"
Question only asked, if [FILTER[11] = 1]
2805L100

SHOW SCREEN-MULTI CHOICE
Q.19A What sort of care or help do you provide for them in the household?

1 ❑ Practical help : such as cooking, cleaning, shopping, doing paperwork, helping with household chores
2 ❑ Nursing-type help : such as helping them to wash or to dress, give medication, helping them to move
3 ❑ Emotional help : such as sitting with them, trying to cheer them up, talking to them about their problems
96 ❑ Other type of care

Question 192

Multiple answers allowed
Answers will be inverted randomly
Open ended answer is written as a bitmap
User defined button : 98 "DK"
User defined button : 99 "Prefer not to say"
Question only asked, if [FILTER[12] = 1]
2905L100

SHOW SCREEN-MULTI CHOICE
Q.19B What sort of care or help do you provide for them outside the household?

1 ❑ Practical help : such as cooking, cleaning, shopping, doing paperwork, helping with household chores
2 ❑ Nursing-type help : such as helping them to wash or to dress, give medication, helping them to move
3 ❑ Emotional help : such as sitting with them, trying to cheer them up, talking to them about their problems
96 ❑ Other type of care

Question 720

Question only asked, if [FILTER[23] = 1]

Q.20 Thinking about your time at school or college, how much would you agree or disagree with the following statements?

Question 200_1

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3007L2

SHOW SCREEN AND READ OUT STATEMENT
My grades are better than average

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 200_2

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3011L2

SHOW SCREEN AND READ OUT STATEMENT
My attendance is better than average

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 200_3

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3015L2

SHOW SCREEN AND READ OUT STATEMENT
I enjoy going to school or college

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 200_4

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3019L2

SHOW SCREEN AND READ OUT STATEMENT
I think I will leave school or college feeling proud of my achievements

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 200_5

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3023L2

SHOW SCREEN AND READ OUT STATEMENT
I get into a lot of trouble

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 200_6

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3027L2

SHOW SCREEN AND READ OUT STATEMENT
I have trouble making friends

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 200_7

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3031L2

SHOW SCREEN AND READ OUT STATEMENT
I get involved with a lot of after school or college activities

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 200_8

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3035L2

SHOW SCREEN AND READ OUT STATEMENT
I often hand my homework in late

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 200_9

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3039L2

SHOW SCREEN AND READ OUT STATEMENT
I find it hard to concentrate in lessons

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 200_10

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3043L2

SHOW SCREEN AND READ OUT STATEMENT
I am being bullied at school or college

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 7103

Multiple answers allowed
Question only asked, if [RAN 1]
3045L100

DUMMY TO RESERVE COLUMNS

Question 721

Question only asked, if [FILTER[23] = 1]

Q.21 Here is a list of things that people do to help around the house. Thinking of the last month, please say which of these you think you have done a lot, some of the time, a little or not at all?

Question 210_1

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3147L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Cleaned your bedroom

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 210_2

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3151L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Cleaned rooms other than bedroom

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 210_3

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3155L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Washed up dishes or load\unload the dishwasher

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 210_4

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3159L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Gone to the shops to buy food

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 210_5

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3163L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Helped prepare or cook meals

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 210_6

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3167L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Helped with decorating or DIY

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 210_7

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3171L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Helped with lifting or carrying heavy things

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 210_8

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3175L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Helped with financial matters like dealing with bills, collecting benefits, going to the bank

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 210_9

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3179L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Worked part-time to help bring money in

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 210_10

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3183L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Interpreted or signed for someone you live with

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 210_11

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3187L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Kept someone in the family company if they can't go out much

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 210_12

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3191L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Taken brothers or sisters to school

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 210_13

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3195L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Looked after brothers or sisters whilst another adult is nearby

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 210_14

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3199L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Looked after brothers or sisters on your own

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 210_15

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3203L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Provided nursing-type help for someone you live with

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 7102

Multiple answers allowed
Question only asked, if [RAN 1]
3205L100

DUMMY TO RESERVE COLUMNS

Question 220

Answers will be displayed in random order
User defined button : 9 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]

SHOW SCREEN
Q.22 Thinking back over the last year, how often would you say you ...?
Never A few times 1 or 2 times a month 1 or 2 times a fortnight More than once a week ...

Question 231

Minimum 0
Maximum 24
Question only asked, if [FILTER[23] = 1]
3308L2

Q.23A Approximately, how many hours do you spend on a typical school or college day helping to care for this person\these people?

Question 232

Minimum 0
Maximum 24
Question only asked, if [FILTER[23] = 1]
3310L2

Q.23B Approximately, how many hours do you spend on a typical day at the weekend or school\college holiday helping to care for this person\these people?

Question 240

Answers will be inverted randomly
User defined button : 98 "DK"
User defined button : 99 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]
3312L2

SHOW SCREEN
Q.24 How would you say your health is in general?

1 ❑ Very Good
2 ❑ Good
3 ❑ Bad
4 ❑ Very Bad

Question 250

Answers will be displayed in random order
User defined button : 9 "Prefer not to say"
Question only asked, if [FILTER[23] = 1]

SHOW SCREEN
Q.25 In the last week how often have you...
A lot Sometimes Almost never ...

Question 260

User defined button : 98 "DK"
Question only asked, if [FILTER[23] = 1]
3320L2

Q.26 Have you received an assessment of your needs by the Local Authority separate from the person you care for?
The Local Authority could be the council or a local government agency.

1 ❑ Yes
2 ❑ No

Question 270

Multiple answers allowed
Answers will be inverted randomly
User defined button : 97 "will not be displayed"
User defined button : 98 "DK"
Question only asked, if [FILTER[23] = 1]
3322L100

SHOW SCREEN-MULTI CHOICE
Q.27 Do you receive support for yourself in your caring role from any of the following?

1 ❑ Social services
2 ❑ Health services
3 ❑ School
4 ❑ A young carers' project
5 ❑ A charity (other than a young carer's project)
6 ❑ Someone else

Question 280

Answers will be inverted randomly
Answer categories mentioned in question 270 will be displayed
Question only asked, if [FILTER[13] = 1]

SHOW SCREEN
Q.28 Thinking of the support that you receive from these sources, how much do you feel each type of support meets your needs?
Fully meets my needs Partly meets my needs Does not meet my needs at all Don't know

Question 413

Multiple answers allowed
Question only asked, if [FILTER[30] = 1]
3432L100

SHOW SCREEN-MULTI CHOICE
Q.4A And what is\are the age(s) of the child(ren)?

1 ❑ 5 years old
2 ❑ 6 years old
3 ❑ 7 years old
4 ❑ 8 years old
5 ❑ 9 years old
6 ❑ 10 years old
7 ❑ 11 years old
8 ❑ 12 years old
9 ❑ 13 years old
10 ❑ 14 years old
11 ❑ 15 years old
12 ❑ 16 years old
13 ❑ 17 years old

Continue at question 70103_1
Continue at question 70103_2
Continue at question 70103_3
Continue at question 70103_4
Continue at question 70103_5
Continue at question 70103_6
If [cntQ4a3 = 0] otherwise continue at question 70113

Question 423

Multiple answers allowed
Question only asked, if [FILTER[30] = 1]
3572L100

Q.4B And what is the name of the <?>?

Question 7703

Question only asked, if [FILTER[30] = 1]

Q.7 Thinking about <Question 423>’s time at school or college, how much would you agree or disagree with the following statements?

Question 703_1

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3674L2

SHOW SCREEN AND READ OUT STATEMENT
His\her grades are better than average

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 703_2

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3678L2

SHOW SCREEN AND READ OUT STATEMENT
His\her attendance is better than average

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 703_3

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3682L2

SHOW SCREEN AND READ OUT STATEMENT
He\she enjoys going to school or college

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 703_4

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3686L2

SHOW SCREEN AND READ OUT STATEMENT
I think he\she will leave school or college feeling proud of his\her achievements

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 703_5

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3690L2

SHOW SCREEN AND READ OUT STATEMENT
He\she gets into a lot of trouble

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 703_6

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3694L2

SHOW SCREEN AND READ OUT STATEMENT
He\she has trouble making friends

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 703_7

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3698L2

SHOW SCREEN AND READ OUT STATEMENT
He\she gets involved with a lot of after school or college activities

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 703_8

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3702L2

SHOW SCREEN AND READ OUT STATEMENT
He\she often hands his\her homework in late

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 703_9

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3706L2

SHOW SCREEN AND READ OUT STATEMENT
He\she finds it hard to concentrate in lessons

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 703_10

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3710L2

SHOW SCREEN AND READ OUT STATEMENT
He\she is being bullied at school or college

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 7803

Question only asked, if [FILTER[30] = 1]

Q.8 Here is a list of things that people do to help around the house. Thinking of the last month, please say which of these you think <Question 423> has done a lot, some of the time, a little or not at all?

Question 803_1

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3744L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Cleaned his\her bedroom

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 803_2

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3748L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Cleaned rooms other than bedroom

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 803_3

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3752L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Washed up dishes or loaded\unloaded the dishwasher

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 803_4

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3756L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Gone to the shops to buy food

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 803_5

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3760L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Helped prepare or cook meals

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 803_6

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3764L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Helped with decorating or DIY

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 803_7

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3768L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Helped with lifting or carrying heavy things

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 803_8

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3772L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Helped with financial matters like dealing with bills, collecting benefits, going to the bank

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 803_9

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3776L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Worked part-time to help bring money in

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 803_10

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3780L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Interpreted or signed for someone he\she lives with

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 803_11

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3784L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Kept someone in the family company if they can't go out much

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 803_12

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3788L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Taken brothers or sisters to school

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 803_13

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3792L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Looked after brothers or sisters whilst another adult is nearby

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 803_14

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3796L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Looked after brothers or sisters on his\her own

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 803_15

Answers will be inverted randomly
Question only asked, if [FILTER[30] = 1]
3800L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month <Question 423> has ...
Provided nursing-type help for someone he\she lives with

1 ❑ A lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 903

Answers will be displayed in random order
Question only asked, if [FILTER[30] = 1]

SHOW SCREEN
Q.9 Thinking back over the last year, how often would you say <Question 423> has...?
Never A few times 1 or 2 times a month 1 or 2 times a fortnight More than once a week ...

Question 1603

Answers will be inverted randomly
User defined button : 98 "DK"
User defined button : 99 "Prefer not to say"
Question only asked, if [FILTER[30] = 1]
3905L2

SHOW SCREEN
Q.16 How would you say <Question 423>'s health is in general?

1 ❑ Very Good
2 ❑ Good
3 ❑ Bad
4 ❑ Very Bad

Question 10003

Open ended answer is written as a bitmap
User defined button : 96 "R"
Question only asked, if [FILTER[30] = 1]
3907L2

SHOW SCREEN
Q.A What is <Question 423>'s ethnic group?
(IF NECESSARY: By this I mean your cultural background)
*HEADING A. White

1 ❑ White British
2 ❑ White Irish
3 ❑ Any other white background

*HEADING B. Mixed

4 ❑ White & Black Caribbean
5 ❑ White & Black African
6 ❑ White & Asian
7 ❑ Any other mixed background

*HEADING E. Chinese or other Ethnic group

15 ❑ Chinese
16 ❑ Any other

*HEADING C. Asian or Asian British

8 ❑ Indian
9 ❑ Pakistani
10 ❑ Bangladeshi
11 ❑ Any other Asian background

*HEADING D. Black or Black British

12 ❑ Caribbean
13 ❑ African
14 ❑ Any other Black background

Question 2020

Answers will be inverted randomly
Open ended answer is written as a bitmap
Question only asked, if [FILTER[31] = 1]
3909L2

SHOW SCREEN

Q.B We would like to ask <Question 42> a few questions about their role in the family. Would that be okay and is he\she available now?

1 ❑ Agree to child be interviewed and child is available INTERVIEWER COLLECT SIGNATURE
2 ❑ Agree to child be interviewed and child is not available
3 ❑ Disagree - would prefer child not to be interviewed

If [Q2020 , 2 , 3] go to end of questionnaire

Question 1011

Question only asked, if [FILTER[31] = 1]

INTERVIEWER: NOW PLEASE ASK FOR THE PARENT\GUARDIAN TO ASK THE CHILD TO COME AND BE INTERVIEWED.

Question 7731

Answers will be inverted randomly
Question only asked, if [FILTER[31] = 1]
3911L2

SHOW SCREEN

Q.C Can I ask for the child’s permission to be interviewed?

1 ❑ Child Agreed
2 ❑ Child Refused

If [Q7731 , 2] go to end of questionnaire

Question 7204

Question only asked, if [FILTER[31] = 1]

Q.20 Thinking about your time at school or college, how much would you agree or disagree with the following statements?

Question 2004_1

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
3915L2

SHOW SCREEN AND READ OUT STATEMENT
My grades are better than average

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 2004_2

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
3919L2

SHOW SCREEN AND READ OUT STATEMENT
My attendance is better than average

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 2004_3

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
3923L2

SHOW SCREEN AND READ OUT STATEMENT
I enjoy going to school or college

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 2004_4

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
3927L2

SHOW SCREEN AND READ OUT STATEMENT
I think I will leave school or college feeling proud of my achievements

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 2004_5

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
3931L2

SHOW SCREEN AND READ OUT STATEMENT
I get into a lot of trouble

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 2004_6

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
3935L2

SHOW SCREEN AND READ OUT STATEMENT
I have trouble making friends

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 2004_7

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
3939L2

SHOW SCREEN AND READ OUT STATEMENT
I get involved with a lot of after school or college activities

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 2004_8

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
3943L2

SHOW SCREEN AND READ OUT STATEMENT
I often hand my homework in late

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 2004_9

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
3947L2

SHOW SCREEN AND READ OUT STATEMENT
I find it hard to concentrate in lessons

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 2004_10

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
3951L2

SHOW SCREEN AND READ OUT STATEMENT
I am being bullied at school or college

1 ❑ Agree strongly
2 ❑ Agree slightly
3 ❑ Neither agree nor disagree
4 ❑ Disagree slightly
5 ❑ Disagree strongly

Question 71034

Multiple answers allowed
Question only asked, if [RAN 1]
3953L100

DUMMY TO RESERVE COLUMNS

Question 7214

Question only asked, if [FILTER[31] = 1]

Q.21 Here is a list of things that people do to help around the house. Thinking of the last month, please say which of these you think you have done a lot, some of the time, a little or not at all?

Question 2104_1

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4055L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Cleaned your bedroom

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 2104_2

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4059L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Cleaned rooms other than bedroom

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 2104_3

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4063L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Washed up dishes or load\unload the dishwasher

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 2104_4

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4067L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Gone to the shops to buy food

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 2104_5

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4071L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Helped prepare or cook meals

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 2104_6

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4075L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Helped with decorating or DIY

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 2104_7

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4079L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Helped with lifting or carrying heavy things

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 2104_8

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4083L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Helped with financial matters like dealing with bills, collecting benefits, going to the bank

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 2104_9

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4087L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Worked part-time to help bring money in

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 2104_10

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4091L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Interpreted or signed for someone you live with

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 2104_11

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4095L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Kept someone in the family company if they can't go out much

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 2104_12

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4099L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Taken brothers or sisters to school

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 2104_13

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4103L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Looked after brothers or sisters whilst another adult is nearby

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 2104_14

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4107L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Looked after brothers or sisters on your own

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 2104_15

Answers will be inverted randomly
User defined button : 98 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4111L2

SHOW SCREEN AND READ OUT STATEMENT
So in the last month have you....
Provided nursing-type help for someone you live with

1 ❑ Done a lot
2 ❑ Some of the time
3 ❑ A little
4 ❑ Not at all

Question 71024

Multiple answers allowed
Question only asked, if [RAN 1]
4113L100

DUMMY TO RESERVE COLUMNS

Question 2204

Answers will be displayed in random order
User defined button : 9 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]

SHOW SCREEN
Q.22 Thinking back over the last year, how often would you say you ...?
Never A few times 1 or 2 times a month 1 or 2 times a fortnight More than once a week ...

Question 2404

Answers will be inverted randomly
User defined button : 98 "DK"
User defined button : 99 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]
4216L2

SHOW SCREEN
Q.24 How would you say your health is in general?

1 ❑ Very Good
2 ❑ Good
3 ❑ Bad
4 ❑ Very Bad

Question 2504

Answers will be displayed in random order
User defined button : 9 "Prefer not to say"
Question only asked, if [FILTER[31] = 1]

SHOW SCREEN
Q.25 In the last week how often have you...
A lot Sometimes Almost never ...

End of questionnaire

Appendix H. Survey questions on the nature and impact of caring responsibilities

This module presented questions that we reviewed in the feasibility report that we felt could be addressed to the young person (aged 10 to 15) which can be adapted for parents to answer by proxy for younger children or adults on their own behalf, if aged 16 or 17. The recommended average length for a self-completion module of this type would be between 5 and 10 minutes. Respondents to be selected through the single screening question proposed for the Crime Survey for England and Wales. They would then also be asked the more thorough prevalence questions to ensure consistency with measurement in the random household survey.

Our suggestions are based on our review of relevant questionnaires : either using questions directly or adapting elements of previous questions into a new form.

Demographics

An Omnibus survey collects key demographic image as standard. These are additional questions that we propose to identify vulnerable groups.

Language
Can I check, is English your first or main language?

INTERVIEWER: If 'Yes', Probe - 'Is English the only language you speak or do you speak any other languages, apart from languages you may be learning at school as part of your studies?'

1. Yes - English only,
2. Yes - English first/main and speaks other languages,
3. No, another language is respondent's first or main language,
4. Respondent is bilingual

Don't know
Refused

{If English is not only language}
Other Languages
Apart from English, what language(s) do you use regularly?

DO NOT READ OUT

1. Bengali,
2. Gujarati
3. Polish
4. Punjabi
5. Somali
6. Urdu
7. Other (specify)

Don't know
Refused

Ethnicity
What is your ethnic group?

Choose one option that best describes your ethnic group or background

White
1. English / Welsh / Scottish / Northern Irish / British
2. Irish
3. Gypsy or Irish Traveller
4. Any other White background, please describe

Mixed / Multiple ethnic groups
5. White and Black Caribbean
6. White and Black African
7. White and Asian
8. Any other Mixed / Multiple ethnic background, please describe

Asian / Asian British
9. Indian
10. Pakistani
11. Bangladeshi
12. Chinese
13. Any other Asian background, please describe

Black / African / Caribbean / Black British
14. African
15. Caribbean
16. Any other Black / African / Caribbean background, please describe

Other ethnic group
17. Arab
18. Any other ethnic group, please describe
Don't know
Refused

Religion
What is your religion?
CODE ONE ONLY
1. No religion
2. Christian (including Church of England, Catholic, Protestant and all other Christian denominations)

3. Buddhist
4. Hindu
5. Jewish
6. Muslim
7. Sikh
8. Any other religion (please specify)
Don't know
Refused

Health
How is your health in general? Would you say it was

1. Very good
2. Good
3. Bad, or
4. Very bad?
Don't know
Refused

Caring

Health of other household members.

Is there anyone who you live with, including yourself, who has a long-standing physical or mental illness or disability, or anyone who misuses drugs or alcohol?

Yes
No

Number with conditions

And can I just check how many people are there in this household with these conditions?
Numeric

If yes

Relationship of sick or disabled household member to the respondent

And what is [their relationship/ the relationship of these people] to you?[49]
Multicode

- Myself
- Mother / Step mother
- Father / Step father
- Brother
- Sister
- Grandmother
- Grandfather
- Aunt
- Uncle
- Other relative (specify)
- Other non-relative (specify)

Whether provide any care for the sick or disabled household member

Do you provide any care for [care recipeient[50]][51] This could be:

- practical help: such as cooking, cleaning, helping with household chores, going to the shops
- nursing-type help: such as helping them to wash or to dress, give medication, helping them to move
- emotional help: such as sitting with them, trying to cheer them up, talking to them about their problems

- Yes
- No

If yes

Type of care provide inside the household (for each care receipt)

What sort of care or help do you provide for [person]?

CODE ALL THAT APPLY

- Practical help: such as cooking, cleaning, helping with household chores, going to the shops
- Nursing-type help: such as helping them to wash or to dress, give medication, helping them to move

[49] All questions repeated according to the number of people in the household with conditions.
[50] Although repetitious this allows us to clarify who is receiving the care from the young person if there is more than one person with a condition.
[51] Textfill repeated for each identified care recipient

- Emotional help: such as sitting with them, trying to cheer them up, talking to them about their problems
- Other care or help (Specify)
- Don't know
- Don't want to answer

Whether cares outside the household
And now thinking about people outside of the household. Do you provide any care on an ongoing basis for anyone that you do not live with who has a long-standing physical or mental illness or disability, or anyone who misuses drugs or alcohol? For example, a family member, friend or neighbour.

Yes
No
Don't Know
Don't want to answer

If yes
Relationship to care recipient outside the household
And what is [their relationship/ the relationship of these people] to you?[52]

- Myself
- Mother / Step mother
- Father / Step father
- Brother
- Sister
- Grandmother
- Grandfather
- Aunt
- Uncle
- Other relative (specify)
- Other non-relative (specify)

Type of care outside the household
What sort of care or help do you provide for [care recipient]?
CODE ALL THAT APPLY

- Practical help: such as cooking, cleaning, helping with household chores, going to the shops
- Nursing-type help: such as helping them to wash or to dress, give medication, helping them to move
- Emotional help: such as sitting with them, trying to cheer them up, talking to them about their problems
- Other care or help (Specify)
- Don't know
- Don't want to answer

For each person cared for:

Hours on a school day

52

How many hours on a typical school day would you say you spend caring for [recipient name][53]?

Numeric
Don't know/no typical day
Don't want to answer

Hours at the weekend/holidays

And how many hours on a typical weekend or school holiday would you say you spend caring for [recipient name][54]?

Numeric
Don't know/no typical day
Don't want to answer

Type of illness/disability

Do you know what type of illness or disability [recipient name] has?

1. Yes
2. No

Don't know
Refused

{If do not what type of illness or disability}

What it this?

Open-ended [to be coded, or potentially long list of conditions]
Refused

Whether diagnosed

Has [recipient name]'s illness or disability been diagnosed by a Doctor or other health professional?

1. Yes
2. No

Don't know
Refused

Whether receives help

Does [recipient name] receive help from health, social care or any other organisation for their illness or disability?

1. Yes
2. No

Don't know
Refused

{If does receive help}

What kind of help do they receive?

Open-ended [for coding]
Don't know
Refused

Other help

Does anyone else who you live with provide help for [recipient's name]?

1. Yes
2. No

[53] Repeated for each identified care recipient
[54] Repeated for each identified care recipient

Don't know
Refused

{If someone else does provide help}
Who else provides help?

- Mother / Step mother
- Father / Step father
- Brother
- Sister
- Grandmother
- Grandfather
- Aunt
- Uncle
- Other relative (specify)
- Other non-relative (specify)

Caring Tasks
I'll now a list stating some of the jobs that children sometime to do help around the house. Think about the help you have provided over the last month and tell me whether you have done it a lot of the time, some of the time of not at all?

1. Clean your own bedroom
2. Clean other rooms
3. Wash up dishes or put dishes in a dishwasher
4. Decorate rooms
5. Take responsibility for shopping for food
6. Help with lifting or carrying heavy things
7. Help with financial matters such as dealing with bills, banking money, collecting benefits

8. Work part time to bring money in
9. Interpret, sign or use another communication system for the person you care for
10. Help the person[s] you care for to dress or undress
11. Help the person[s] you care for to have a wash
12. Help the person[s] you care for to have a bath or shower
13. Keep the person[s] you care for company e.g. sitting with them, reading to them, talking to them

14. Keep an eye on the person you care for to make sure they are alright
15. Take the person you care for out e.g. for a walk or to see friends or relative
16. Take brothers or sisters to school
17. Look after brothers or sisters whilst another adult is near by
18. Look after brothers or sisters on your own

    1. A lot of the time
    2. Some of the time
    3. Not at all

    Don't know
    Don't want to answer

Although this overlaps with the question asking about care for the care recipient it encompasses a wider range of tasks the young person might undertake to help indirectly, particularly caring for siblings.

Impact of caring

All questions in tables have the option of 'don't know' or 'don't want to answer'

Thinking back over the last 12 months, that is since [date]:

On education

		More than once a week	1-2 times a fortnight	1-2 times a month	Less or never
a.	Were you late for school?				
b.	Were you absent from school?				
c.	Did you fall asleep during class?				

Now thinking about your time at school, please say to what extent you agree or disagree with the following statements.

		Strongly agree	Somewhat agree	Neither nor	Somewhat disagree	Strongly disagree
a.	My grades are better than average					
b.	My attendance is better than average					
c.	I enjoy going to school					
d.	I think I will leave school feeling proud of my achievements					
e.	I get into a lot of trouble					
f.	I have trouble making friends					
g.	I get involved with a lot of after school and					

	extracurricular activities					
h.	My parents think it is very important that I get my homework completed on time and to a high standard					
i.	I find it hard to concentrate in lessons					

On emotional well being

In the last month, how often have you…

		Almost all of the time	Some of the time	Almost never
a.	Felt sad			
b.	Felt lonely			
c.	Felt happy			
d.	Laughed			
e.	Cried			
f.	Felt angry			
g.	Felt stressed			

And more generally,

		A lot	Sometimes	Almost never
a.	How often do you have time for yourself?			

b.	How often do you feel like there's no one you can depend on but yourself?			
c.	How often do you feel angry about all the things you have to do?			
d.	How often do you feel like people expect too much from you?			
e.	How often do you have to skip a fun activity because you have more important responsibilities?			

[If no to either] Who do you share this kind of news with?

- Parent / family member
- Charity / social worker
- Teacher
- Neighbour
- I keep my problems to myself

		Never	Some of the time	A lot of the time
1.	Because of caring I feel I am doing something good			
2.	Because of caring I feel that I am helping			
3.	Because of caring I feel closer to my family			
4.	Because of caring I feel good about myself			
5.	Because of caring I have to do things that make me upset			
6.	Because of caring I feel stressed			
7.	Because of caring I feel that I am learning useful things			
8.	Because of caring my parents are proud of the kind of person I am			

9.	Because of caring I feel like running away			
10.	Because of caring I fee l very lonely			
11.	Because of caring I feel like I can’t cope			
12.	Because of caring I can’t stop thinking about what I have to do			
13.	Because of caring I feel so sad I can hardly stand it			
14.	Because of caring I don't think I matter			
15.	Because of caring I like who I am			
16.	Because of caring life doesn’t seem worth living			
17.	Because of caring I have trouble staying awake			
18.	Because of caring I feel I am better able to cope with problems			
19.	I feel good about helping			
20.	Because of caring I feel I am useful			

Department for Education

© TNS BMRB

Reference: DFE-RR637

ISBN: 978-1-78105-700-1

This research was commissioned under the 2010 to 2015 Conservative and Liberal Democrat coalition government. As a result the content may not reflect current Government policy. The views expressed in this report are the authors' and do not necessarily reflect those of the Department for Education.

Any enquiries regarding this publication should be sent to us at: In-Placement.CiC@education.gov.uk or www.education.gov.uk/contactus

This document is available for download at www.gov.uk/government/publications