

Carers Census

Specification for data collection on:

- **Carers Assessments / Adult Carers Support Plan / Young Carers Statement**
- **Support for carers**

to provide baseline data for 2017-18 and to monitor the Carers Act being implemented on 1 April 2018.

Carers Census

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Carers Census

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Carers Census

Specification for Carers Census 2017 data collection

Version history

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0.5	29/7/2016	Draft	Julie Rintoul	Incorporating comments / discussion at 2 nd meeting of SLWG
0.6	19/08/2016	Draft	Julie Rintoul	Incorporating comments from Mike Brown, Social Work Scotland and Chair of Short Life Working Group
0.7	26/9/2016	Draft	Julie Rintoul	Updated following third meeting of SLWG on 24 th August
0.8	13/10/2016	Draft	Julie Rintoul	Further revisions incorporating comments from Mike Brown, SLWG Chair

Carers Census

Contents

Introduction.....	6
Data Definitions for the Carers Census	11
Carer data.....	15
Cared-for person data	23
Carer assessment data	29
Additional data for YCS.....	36
Annex - Description of client groups	37

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Carers Census

Introduction

Why is the Scottish Government collecting this information?

The census collects information which will be used by the Scottish Government, COSLA, Health and Social Care Partnerships, Local Authorities and other stakeholders to monitor the implementation of the Carers Act. The Carers Act will be implemented on the 1st April 2018 but it is important to collect data for the year prior to implementation so that the impact of the Act can be assessed. Analysis of this information will let all stakeholders understand how the Act changes the number of requests for assessment, the number completed, and the types of support which carers require. It will help the Scottish Parliament, the Scottish Government, carers' organisations and other stakeholders to understand how the new Act is making a difference to the lives of carers across Scotland. The Census will also inform discussions on future funding needs for support to carers.

Who will use information from the census?

We expect statistical analysis from the census to be used by many different people and organisations such as:

- Scottish Government
- COSLA
- Local Authorities
- Integration partnerships
- NHS Boards
- National Carers Organisations
- Social Work Scotland
- Third Sector
- Carers
- Academics
- Approved researchers with an interest in Carers and Social Care
- Members of the Public
- MSPs

Carers Census

Who will provide the information?

All agencies providing assessment, Adult Carer Support Plans, Young Carers Statements, and/or services to support carers. This will include: Integration partnerships, Local Authorities, NHS Boards, and third sector agencies

Who can I contact if I want to ask questions on the guidance notes?

Julie Rintoul
Health & Social Care Analysis
Scottish Government
Telephone: 0131 244 5366
e-mail: SWStat@scotland.gsi.gov.uk

Who can I contact if I want to ask questions on IT/ ProcXed.Net?

ScotXed Unit
Scottish Government
Telephone: 0131 244 8492
e-mail: ScotXed@gov.scot

When will the census happen?

xxx

When do I have to submit the data by?

xxx

What is the purpose of this document

These notes have been prepared by the Scottish Government to assist local authorities with the collection and submission of data.

Carers Census

Who should be included in the census?

Data should be returned for all carers known to partnerships (Health, Social Care, Carers Centres, third sector) and other organisations who provide assessment and/or support for carers on behalf of local authorities.

This includes all persons who meet any of the following criteria:

- have had an assessment or review of their needs as carers during the reporting period; or
- have been offered a carer's assessment, ACSP or YCS during the reporting period (including those who turned down the offer of assessment); or
- have requested a carer's assessment, ACSP or YCS during the reporting period; or
- have received one or more of the support services in the list below at any time during the reporting period; or
- care for a person who has received respite or replacement care at any time during the reporting period;

For the 2017-18 data collection prior to the introduction of the Carers Act, Adult Carer Support Plan / Young Carer Statement should be interpreted as your current Carers Assessment process.

Support services

A carer who has received one or more of the services listed below should be included in the data returned.

- short breaks or respite
- information and advice
- practical support (e.g. transport, equipment, adaptations)
- counselling or emotional support
- training or learning
- advocacy services
- help applying for carer's allowance and other financial assistance
- a "carers payment" made by a local authority or IJB

Carers Census

Do Scottish Government collect any other information on carers?

Carers who receive self-directed support to purchase services or support are currently included in the Social Care Census. The client group categories in the Social Care Census allow identification of whether someone is a carer as well any disabilities or long-term conditions. The full data collected in the Social Care Survey can be found at:

<http://www.gov.scot/Topics/Statistics/Browse/Health/SocialCareSurvey> and includes:

For each carer:

- postcode
- date of birth
- gender
- ethnic group

If receiving Self-Directed Support:

- SDS options chosen
- SDS start date
- SDS end date
- SDS total package value
- Assessed needs e.g. short break

Note that information on SDS is not collected in this census but can be linked to the Carers Census using the unique identifier provided for the carer.

Carers Census

What is collected in the Carers Census?

For each Carer:

- Local Authority code
- ID Carer
- CHI number
- surname*
- forename*
- postcode
- date of birth
- gender
- ethnic group
- care duration
- care hours
- care type
- care level
- care level (able, willing to provide)
- care impact
- care received

For the person they care for:

- ID Carer
- Unique ID for cared for person |
- CHI number (cared for person)
- surname*
- forename*
- postcode OR does carer live with cared for person
- date of birth OR agegroup

- gender
- ethnic group
- client group
- relationship to carer

For Adult Care Support Plan / Young Carers Statement:

- source of referral for ACSP / YCS
- date ACSP / YCS requested / offered
- type of ACSP / YCS – new or review
- ACSP / YCS completed?
- date completed
- ACSP / YCS declined
- date declined
- ACSP / YCS joint assessment with cared for person
- is carer willing and able to care
- is carer eligible for support
- eligibility criteria
- carers support needs
- support provided / purchased by LA
- did review result in change to support
- what conditions would trigger a review

For Young Carers Statement:

- responsible Authority for young carer
- extent to which responsible authority feels care provided by young carer is appropriate

Commented [MD1]: Will be updated when final variables agreed.

Commented [M2]: Are these not also needed for the cared for person? Eg for bullet 5 of the record selection criteria. Also presupposed on page 24

Carers Census 2017

Data Definitions : Carer

Carer

An individual who provides or intends to provide care for another individual (the “cared-for person”), except where:

- the care is or would be provided under or by virtue of a contract, or as voluntary work.
- in the case of a cared-for person under 18 years old, to the extent that the care is or would be provided by virtue of the person's age

Taken from [Section 1 of the Carers \(Scotland\) Act 2016](#)

Young carer

A carer who is either under 18 years old, or has reached age 18 while still at school, and is still at school. Taken from [Section 2 of the Carers \(Scotland\) Act 2016](#).

Adult carer

A carer who is at least 18 years old, and not a young carer. Taken from [Section 3 of the Carers \(Scotland\) Act 2016](#).

Carers Census 2017

Data Definitions : Carer Assessments / Reviews

Assessment/review

The first/initial assessment of the carer's needs is described in this data specification as an assessment, with any subsequent assessment described as a review. Prior to 1 April 2018 when the Carers Bill is implemented, any reference to assessment or review refers to the arrangements each council has in place to support Carers. From 1 April 2018 onwards, this refers to the ACSP / YCS as specified in the Carers Act.

Adult Carer Support Plan (ACSP)

This is a plan prepared by a responsible local authority setting out:

- (a) an adult carer's identified personal outcomes
- (b) an adult carer's identified needs (if any)
- (c) the support (if any) to be provided by the responsible local authority to an adult carer to meet those needs

Taken from [section 6\(1\) of Carers \(Scotland\) Act 2016](#).

Young Carer Statement (YCS):

This is a statement prepared by a responsible authority setting out:

- (a) a young carer's identified personal outcomes
- (b) a young carer's identified needs (if any)
- (c) the support (if any) to be provided by the responsible local authority to a young carer to meet those needs

Taken from [section 12\(1\) of the Carers \(Scotland\) Act 2016](#).

Offered

An assessment/review is offered if the process was initiated by the local authority/partnership/other organisation rather than the carer.

Requested

An assessment/review is requested if the process was initiated by the carer rather than the local authority/partnership/other organisation.

Carers Census 2017

Data Definitions : Support to Carers

Support services

- Short breaks or respite: Where arrangements are put in place that allow the carer to have a break from their normal routine and their caring responsibilities. This can be during the day or overnight, for a few hours, a few days or longer, and for the carer, cared-for person or both together.
- Information and advice: Where the carer receives information/advice on their caring role, particularly where they are new to caring or there are changes to the caring situation.
- Practical support:
- Counselling/emotional support: Providing or enabling access to emotional support to help the carer to cope with the demands of caring. This can be in the form of one-to-one discussion, peer support groups and training sessions, or passing on contact details for support services.
- Training or learning: Activities intended to improve the carer's knowledge, skills, mental health and ability to cope with their caring responsibilities.
- Advocacy services: Where a person independent from the local authority/NHS/service provider provides assistance through helping to safeguard the carer's rights, access information and making sure that the carer's voice is heard.
- Help with financial issues: This may include checks on benefit entitlements (such as the Carers Allowance), help with filling out forms for benefits, grants and allowances, and direction towards relevant financial and advice services.
- Carer's payment: a scheme operated by some agencies whereby eligible carers may apply for a small annual payment to assist their caring role

Replacement care

A component of a short break - the care provision for the cared-for person that is required to allow the carer to have a short break from their caring responsibilities. (Agencies may be recording replacement care under the term "respite")

Carers Census 2017

Eligibility criteria

The criteria by which the local authority must determine whether it is required to provide support to carers to meet carers' identified needs. ([Sections 21 and 23 of the Carers \(Scotland\) Act 2016](#))

Data Definitions : Other

Responsible local authority

The local authority for the area in which the cared-for person resides. ([Section 41 of the Carers \(Scotland\) Act 2016](#))

Responsible authority

In relation to a young carer, the responsible authority is:

- the health board in which the young carer resides, where the young carer is a pre-school child
- the local authority in which the young carer resides, where the young carer is not a pre-school child

Taken from [Section 19 of the Carers \(Scotland\) Act 2016](#), but please note the special cases in [Section 20](#).

A "pre-school child" is a child who:

- has not commenced attendance at a primary school, and
- if the child is of school age, has not commenced attendance at a primary school because the relevant local authority has consented to the child's commencement at primary school being delayed.

Taken from [Section 36\(3\) of the Children and Young People \(Scotland\) Act 2014](#).

Reporting period

The period covered by the Carers Census - this is specified under 'Coverage' on page 2.

Carers Census 2017

Carer data

One record for each carer should be included in the data submitted.

Variable Name	Description	Format/Values	Additional information
LocalAuthority	The 'responsible local authority', as defined in the Carers Act, i.e. the local authority for the area in which the cared-for person resides.	100 Aberdeen City 110 Aberdeenshire 120 Angus 130 Argyll & Bute 150 Clackmannanshire 170 Dumfries & Galloway 180 Dundee City 190 East Ayrshire 200 East Dunbartonshire 210 East Lothian 220 East Renfrewshire 230 Edinburgh, City of 240 Falkirk 250 Fife 260 Glasgow City 270 Highland 280 Inverclyde 290 Midlothian 300 Moray 235 Na h-Eileanan Siar 310 North Ayrshire 320 North Lanarkshire	This must be provided for all carers. This identifies the area that is providing support to the carer. This support may be provided by the local authority, IJB, local carers centre and/or health board. 330 Orkney Islands 340 Perth & Kinross 350 Renfrewshire 360 Shetland Islands 370 South Ayrshire 380 South Lanarkshire 390 Stirling 395 Scottish Borders 400 West Lothian

Carers Census 2017

Variable Name	Description	Format/Values	Additional information
IDCarer	Unique identifier for the carer.	Numeric/Character	<p>This must be provided for all carers.</p> <p>The variable IDCarer must be unique to a particular client within the local authority or organisation providing the data. It may be the unique identifier used your organisation's MIS or may be generated for the purposes of the data return. If the unique care ID is generated, it must be consistent to the client across all datasets returned for the carers' assessment data collection and the Social Care Survey and repeatable over time. This is important to ensure that Carers can be identified as both providing care and receiving services.</p> <p>Where a carer appears in more than one dataset, they should have the same unique ID in each - this also applies to data relating to different years/quarters/etc. to allow for longitudinal analysis.</p>

Carers Census 2017

Variable Name	Description	Format/Values	Additional information
CHI	<p>Community Health Index (CHI) number for the carer.</p> <p>The CHI is a population register, used in Scotland for health care purposes. The CHI number uniquely identifies a person on the index.</p>	10-digit number	<p>Optional at present as aware that not all organisations store CHI number. Useful to link data submitted by different organisations to identify carers that engage with e.g. local carers centre and the local authority.</p> <p>The data provided will be one-way encrypted once the data has been uploaded to procd.net to protect patient privacy. This means that the Scottish Government will not be able to see the CHI number, but instead a string of numbers and characters.</p> <p>The encryption method used will be shared with the CHI Indexing teams at ISD Scotland and NHS Central Register to enable data linkage.</p>
Surname	Surname/family name of carer.	Character	Required for data linkage/matching/ longitudinal analysis if the council is unable to provide an IDCarer variable or CHI.
Forename	Forename/first name of carer.	Character	Required for data linkage/matching/ longitudinal analysis if the council is unable to provide an IDCarer variable or CHI.

Carers Census 2017

Variable Name	Description	Format/Values	Additional information
Postcode	The postcode of the carer's home address on the date that the assessment was offered/requested.	Standard postcode format, including space. e.g. AB12 3CD	This must be provided for all carers. Must be present and must be a full valid postcode. Postcode will be used as a data quality check with IDCarer. It will also be used to create geography variables such as health board. Postcode can be used for future spatial analysis (e.g. distance carer lives from person they care for). Postcode will be removed from dataset used for statistical analysis. Raw data will be stored in a secure data warehouse. Used for data linkage/matching and geographical analysis.
DateOfBirth	Carer's Date of Birth	DD/MM/YYYY format.	This must be provided for all carers. Only month and year of birth will be passed to statisticians for analysis purposes. Full date of birth will be held separately by ScotXed for data linking purposes. Used for data linkage / matching and for analysis of data by age of carer.
Gender	Gender of the carer.	1 - Male 2 - Female 99 - Not Known	This must be provided for all carers. In future when question developed to identify transgender we may expand this question: http://www.gov.scot/Resource/0039/00393543.pdf Used for data linkage / matching and for analysis of data by gender of carer.

Carers Census 2017

Variable Name	Description	Format/Values	Additional information
EthnicGroup	<p>Ethnicity of the carer.</p> <p>To allow analysis of carer data by ethnic group. The Scottish Government has a clear commitment to equal opportunities under the Equality Act 2010.</p>	<p>01 - White</p> <p>02 - Mixed or multiple ethnic groups</p> <p>03 - Asian, Asian Scottish or Asian British</p> <p>04 - African, Caribbean or Black</p> <p>05 - Other Ethnic Background</p> <p>97 - Not Disclosed</p> <p>99 - Not Known</p>	<p>Ethnic group must be provided for all carers.</p> <p>The purpose of this item is to record the ethnic background of individuals, not nationality or country of birth.</p> <p>Code 97 (Not Disclosed) should only be used where the carer does not want their ethnic background to be recorded. In all other cases where no return has been made by the carer, please use code 99 (Not Known).</p> <p>All local authorities are asked to make reasonable efforts to ensure that ethnic background data are available for all clients.</p> <p>To allow analysis of data by ethnicity for equalities purposes. (LAs need to take impact of having protected characteristic(s) into account - Carers Act S8(2)).</p> <p>For more information on collecting ethnicity data see: http://www.gov.scot/Resource/0039/00394314.pdf</p> <p>This information will enable a national picture to be built of the ethnic background of carers, and this in turn will inform policy development and help the Scottish Government to address identified needs and to deploy resources appropriately.</p>

Carers Census 2017

Variable Name	Description	Format/Values	Additional information
CareDuration	The length of time that the carer has been providing care. Used to provide better understanding of length of time people are carers for and whether support needs change over time.	1 - Less than one year 2 - One year but less than 5 years 3 - 5 years but less than 10 years 4 - 10 years but less than 20 years 5 - 20 years or more 9 - Not Known	This question relates to the carer and the length of time they have been caring. The carer may provide care to more than one person or they may have cared for different people over a period of time. Options taken from question RG18 in the Scottish Health Survey.
CareHours	Number of hours of care that the carer provides in a typical week. Allows us to identify carers doing more than 35 hours per week (threshold for Carers Allowance) and allows for comparison with other surveys and Scotland's Census.	1 - up to 4 hours 2 - 5 - 19 hours 3 - 20 - 34 hours 4 - 35 - 49 hours 5 - 50+ hours 9 - Not Known	This must be provided for all carers and will be the hours of care recorded at the last assessment or review. Exclude any caring that is done as part of paid employment or formal volunteering. If the carer provides care for more than one person, this should be the total amount of care provided. Provides information on the extent of care provided and impact on carer's life (Carers Act s9(1)(a))

Carers Census 2017

Variable Name	Description	Format/Values	Additional information
CareType	Type of care that the carer provides.	1 - Help with medication 2 - Help with personal care 3 - Help with shopping, cleaning, domestic tasks 4 - Help with transport 5 - Support / supervision / emotional support 6 - Financial support 7 - Other 9 - Not Known	This must be provided for all carers. (Multiple responses possible.) Provides information on the extent of care provided and impact on carer's life (Carers Act s9(1)(a))
CareTypeOther	Other types of care provided by the carer not included in the list of options for CareType	Free text	Only required if CareType = 7.
CareLevelWilling	The level of care that the carer is willing to provide.	1 - Not willing to provide care 2 - Willing to provide less than current level of care 3 - Willing to provide current level of care 4 - Willing to provide more than current level of care 9 - Not Known	This must be provided for all carers. Provides information on the extent of care that the carer is able and willing to provide (Carers Act s9(1)(b)). Willingness to provide care may be related to receiving more support.

Carers Census 2017

Variable Name	Description	Format/Values	Additional information
CareLevelAble	The level of care that the carer is able to provide.	1 - Not able to provide care 2 - Able to provide less than current level of care 3 - Able to provide current level of care 4 - Able to provide more than current level of care 9 - Not Known	This must be provided for all carers. Provides information on the extent of care that the carer is able and willing to provide (Carers Act s9(1)(b)). Willingness to provide care may be related to receiving more support.
CareImpact	The impact on the Carer of providing care on the carer.	1. Financial hardship 2. Health & wellbeing 3. Social Isolation 4. Missed opportunities (work, career, education) 5. Other	This must be provided for all carers. Multiple responses possible.
CareImpactOther	Other ways in which providing care has impacted on the carer	Free text	Only required if CareImpact = 5.
CareReceived	Does the carer receive help, support or other assistance in relation to their own care needs?	1 - Yes 0 - No 9 - Not Known	To identify carers who require care for themselves.

Commented [U3]: Not sure we need both of these questions!

Commented [M4]: For discussion at the next meeting. Can we add in something about why we need this?

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Cared-for person data

Section 9(1)(a)(i) of the Carers Act states that an ACSP must contain information about the nature and extent of the care provided or to be provided. This suggests that the data collected should contain information about the cared-for person as well as the carer, or the means to link carers assessment data to a cared-for person dataset (e.g. data from the Social Care Survey).

A Carer may care for more than one person. Multiple Cared for person records can be provided for each carer.

Note that there were privacy concerns at the last meeting regarding the inclusion of detailed information on the cared-for person particularly if the cared for person was not aware that their details were being gathered. To get around this the grey shaded questions could be replaced by the new yellow questions.

Variable Name	Description	Format/Values	Additional information
IDCarer	Unique identifier for the carer.	Numeric/Character	This must be provided for all carers and provides a link to the carer data collected in the section above. IDCarer will not be unique within the cared-for person dataset - for example, if a carer provides care to two people, that carer's IDCarer will appear twice in this dataset.

Commented [M5]: For discussion at the next meeting. The grey shaded data will be known for cared for people already known to the LA, for whom privacy issues are already covered, but won't be known for cared-for people not known to LAs. An alternative approach would be to ask a question whether the cared-for person is already known to the LA (Yes, No, N/k). [Known= recorded somewhere on their MIS]. And then for Yes ask the grey questions, and for No or N/K ask the yellow questions.

Carers Census 2017

Variable Name	Description	Format/Values	Additional information
UniqueID	Unique identifier for the Cared for person	Numeric/Character	<p>This must be provided for all cared-for persons, and should be unique within the cared-for person dataset. If the cared-for person is already known to Social Work then this should be the same identifier used in the Social Care Survey.</p> <p>The cared-for person could also be a carer. Therefore the IDCarer and UniqueID variables should use the same unique identifier for each individual person to allow for identification of dual carer/cared for person relationships and to identify where there are multiple carers for one person or one person caring for multiple people.</p>
CHICFP	Community Health Index number for the cared-for person.	10-digit number	<p>Optional at present as aware that not all local authorities store CHI number. Useful for data linkage projects involving anonymised social care data.</p> <p>The data provided will be one-way encrypted once the data has been uploaded to proxcd.net to protect patient privacy. This means that the Scottish Government will not be able to see the CHI number, but instead a string of numbers and characters.</p> <p>The encryption method used will be shared with the CHI Indexing teams at ISD Scotland and NHS Central Register to enable data linkage in future.</p>
SurnameCFP	Surname/family name of cared-for person.	Character	Required for data linkage/matching/ longitudinal analysis if the council is unable to provide a UniqueID variable or CHI.

Carers Census 2017

Variable Name	Description	Format/Values	Additional information
ForenameCFP	Forename/first name of cared-for person.	Character	Required for data linkage/matching/ longitudinal analysis if the council is unable to provide a UniqueID variable or CHI.
PostcodeCFP	The postcode of the cared-for person's home address on the date that the assessment was offered/requested.	Standard postcode format, including space. e.g. AB12 3CD	<p>This must be provided for all cared for persons. Must be present and must be a full valid postcode.</p> <p>Postcode will also be used to create geography variables such as health board. Postcode can be used for future spatial analysis (e.g. distance carer lives from person they care for). Postcode will be removed from dataset used for statistical analysis. Raw data will be stored in a secure data warehouse.</p> <p>Used for data linkage/matching and geographical analysis.</p>
DateOfBirthCFP	Cared-for person's Date of Birth	DD/MM/YYYY format.	<p>This must be provided for all cared for persons. If exact date of birth is not known then an estimated year of birth can be given as 01/01/YYYY.</p> <p>Only month and year of birth will be passed to statisticians for analysis purposes. Full date of birth will be held separately by ScotXed for data linking purposes.</p> <p>For analysis of data by age of cared-for person and to explore age difference between cared for person and carer.</p>
Agegroup	Cared for person's age group	0–17 School age 18–64 Working age 65+ Retirement age	Replaces question asking for date of birth of cared for person

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Variable Name	Description	Format/Values	Additional information
Does carer live with cared-for person?	Do the carer and cared-for person live together?	1 - Yes 2 - No 9 - Don't know	Replaces question asking for postcode of cared-for person
GenderCFP	Gender of the cared-for person.	1 - Male 2 - Female 99 - Not Known	This must be provided for all clients. For analysis of data by gender of cared-for person.
EthnicGroupCFP	Ethnicity of the cared-for person. To allow analysis of data by ethnic group. The Scottish Government has a clear commitment to equal opportunities under the Equality Act 2010 .	01 - White 02 - Mixed or multiple ethnic groups 03 - Asian, Asian Scottish or Asian British 04 - African, Caribbean or Black 05 - Other Ethnic Background 97 - Not Disclosed 99 - Not Known	Ethnic group must be provided for all carers. The purpose of this item is to record the ethnic background of individuals, not nationality or country of birth. Code 97 (Not Disclosed) should only be used where the carer does not want their ethnic background to be recorded. In all other cases where no return has been made by the carer, please use code 99 (Not Known). All local authorities are asked to make reasonable efforts to ensure that ethnic background data are available for all clients. To allow analysis of data by ethnicity for equalities purposes.

Carers Census 2017

Variable Name	Description	Format/Values	Additional information
ClientGroupCFP	Client group of the cared-for person.	01 - Dementia 02 - Mental Health Problems 03 - Learning Disability 04 - Physical Disability 05 - Addiction 06 - Palliative Care 08 - Problems arising from infirmity due to age Extend this list to include groups relevant for children and young adults. XX - Other 98 - Other vulnerable groups 99 - Not Known	At least one client group must be provided for all cared-for persons, and multiple client groups can be provided if applicable. See Annex for descriptions of the client groups. Provides (contextual) information on the extent of care provided and impact on carer's life (Carers Act s9(1)(a)) <i>Are these groups sufficient to cover all cared-for persons? (e.g. children with ADHD, cared-for person with a purely medical condition) - worth including a free text field to be completed if response is 'Other' to get more detail?</i>
ClientGroupCFPOther	Other client group of the cared-for person, where this is not in the list above for ClientGroupCFP.	Free text	Only required if ClientGroupCFP = XX (update when list for previous item is finalised).

Commented [M6]: Leave for discussion at the SLWG meeting. Note that a person may have more than one client group category.

Commented [MD7]: What additional groups should be added to include conditions/groups more likely to be relevant for children/young people? For example:
 - autism
 - ADHD
 - eating disorders
 (Note that the existing client groups are relatively broad - are these suitable for this data collection, or is something more detailed needed? If the broad groups are suitable, may not be appropriate to add relatively narrow categories like those above.)

Carers Census 2017

Variable Name	Description	Format/Values	Additional information
RelationshipCFP	What is the carer's relationship to the cared-for person?	0 - Not related 1 - Parent 2 - Grandparent 3 - Sibling 4 - Child 5 - Grandchild 6 - Cousin 7 - Aunt/uncle 8 - Niece/nephew 9 - Not Known	Provide the option that best fits the statement: "The carer is the cared-for person's..." Notes: (0) "Not related" includes neighbours and friends (3) "Sibling" includes half-brothers and sisters. Include great grandparents in (2); great uncles and aunt in (7).

Commented [U8]: Is this too detailed?

Commented [M9]: List + defs exhausts family relations?

Comment for discussion at the SLWG – services received by people cared-for:

The Carers Act will increase the number of carers who receive an assessment of their support needs. This is likely to increase demand for assistance with short breaks, and thereby the demand for replacement care for the persons they care for. More assessment is also likely to identify unmet need for other care services, such as home care and direct payments.

Some, but not all, of this information will be captured by the Scottish Government's Social Care Survey, at least for cared-for people already known to local authorities. This does not currently collect data on replacement care. One option to explore, therefore, would be to add replacement care back into the Social Care Survey and use data linkage to link to the Carer Census.

The other option would be to put the services received by people cared-for as a new section in the Carer Census, either here, or after the Carer assessment section, or split between both locations.

Carers Census 2017

Carer assessment data

Variable Name	Description	Format/Values	Additional information
IDCarer	Unique identifier for the carer.	Numeric/Character	This must be provided for all carers.
CASource	What was the source of the referral for an ACSP / YCS / assessment	1 - Requested by carer 2 - Social Work 3 - GP 4. - Other Health/NHS) 5 - Carers Centre 6 - Other	Must be provided for all records. To provide information of the number/ proportion of reviews offered and requested and to determine which bodies are promoting ACSP / YCS / assessment
CADate	Date that the carer assessment was requested/offered.	DD/MM/YYYY format (or whatever date format is appropriate).	Must be provided for all records. To provide information about timescales for assessments and the distribution of requests/offers over the year.
CAType	Type of carer assessment.	1 - New 2 - Review / Re-assessment	Must be provided for all records. To differentiate between new assessments and reviews or re-assessments - will give an indication of time between reviews (when combined with request/offer date).
CAComplete	Has the carer assessment been completed?	1 - Yes 0 - No	Must be provided for all records. To provide information on the number/ proportion of assessments completed.

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Variable Name	Description	Format/Values	Additional information
CADateComp	Date that carer assessment was completed.	DD/MM/YYYY format.	Only required if CAComplete = Yes - must be provided for all of these records. To provide information about timescales for assessments.
CADeclined	Was the carer assessment declined?	1 - Yes 0 - No	Only required if CAComplete = No - must be provided for all of these records. To provide information on the number/ proportion of assessments declined.
DeclineDate	Date that the carer assessment was declined	DD/MM/YYYY format.	Only required if CADeclined = Yes - must be provided for all of these records. To provide information about timescales for assessments.
CAJoint	Was the carer assessment carried out as part of a joint assessment with the cared-for person?	1 - Yes 0 - No 9 - Not Known	Only required if CAComplete = Yes - must be provided for all of these records. To provide information about how assessment is carried out.
CAWilling	Is the carer willing and able to provide care for the cared-for person?	1 - Yes 0 - No 9 - Not Known	Only required if CAComplete = Yes - must be provided for all of these records. To give an indication of the proportion of carers who are not willing/able, as the people that they care for are more likely to need additional support in the future.

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Variable Name	Description	Format/Values	Additional information
CAEligible	Is the carer eligible for support? (There will be eligibility criteria to be met in order for the carer to receive support - does the carer meet these criteria at the time that the assessment was completed?)	1 - Yes 0 - No 9 - Not Known	Only required if CAComplete = Yes - must be provided for all of these records. To provide information about the number/ proportion of carers assessed to need support who are eligible.
Eligibility Criteria	The eligibility category applicable to the carer at time of assessment.	1 - Critical 2 - Substantial 3 - Moderate 4 - Low 5 - None 9 - Not Known	<i>(NB Guidance on eligibility criteria for carers is being drafted for consultation by the Scottish Government. This may change the code-list proposed)</i>

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Variable Name	Description	Format/Values	Additional information
CASupportNeeds	The support needs of the carer identified by the carer assessment.	01 - Short breaks or respite 02 - Advice and information 03 - Practical support (e.g. transport, equipment/adaptions) 04 - Counselling or emotional support 05 - Training and learning 06 - Advocacy services 07 - Personal assistant/support worker/community nurse, etc. 08 - Help from family, friends or neighbours 09 - Carer's allowance 10 - Other 11 - No help/support required 99 - Not Known	Only required if CAComplete = Yes - must be provided for all of these records. Multiple responses possible. All support needs identified should be included, not just those for which the carer is eligible for support. Provides information on carer's support needs (Carers Act S9(1)(f)), and if support should be provided in the form of a break from caring (S9(1)(k)).
CASuppNeedsOther	Other support needs not included in list of options for CASupportNeeds	Free text	Only required if CASupportNeeds = 10.

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Variable Name	Description	Format/Values	Additional information
CASupportProv	The support that the local authority (or an agency acting on behalf of the local authority) provides or intends to provide to the carer. This includes support arranged through other bodies e.g. local advocacy service, carers centre, etc	01 - Short breaks or respite 02 - Advice and information 03 - Practical support (e.g. transport, equipment/adaptions) 04 - Counselling or emotional support 05 - Training and learning 06 - Advocacy services 07 - Personal assistant/support worker/community nurse, etc. 08 - Help from family, friends or neighbours 09 - Assistance with benefits, eg Carer's allowance 10 - Other support 11 - No help/support required 99 - Not Known	Only required if CAComplete = Yes - must be provided for all of these records. Multiple responses possible. Provides information on the support provided to the carer (Carers Act S9(1)(i/j)), and if support will be provided in the form of a break from caring (S9(1)(k)).

Commented [M10]: I would re-order list and put this after the split out suggested for 07.

Commented [M11]: I know this follows the Scottish Health Survey, but we need to separate out (a) PAs (b) support workers (Def needed); (c) home care, (d) community health services

Commented [M12]: I think this should be the first option

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Variable Name	Description	Format/Values	Additional information
CASuppProvOther	Other support that the local authority provides/intends to provided to the carer.	Free text	Only required if CASupportProv = 10.
CARReviewOutcome	If the carer assessment was a review, has the assessment resulted in a change to the support provided?	1 - Yes 0 - No	Only required if CAComplete = Yes and CAType = Review To provide information on the number/ proportion of reviews that result in a change to support.
CARReviewCrit	What conditions need to be met to trigger a review/reassessment?	(To be determined)	Only required if CAComplete = Yes - must be provided for all of these records. (Multiple responses possible?) Provides information on what will trigger a review (Carers Act S9(1)(l)).

Commented [U13]: Not sure if we need this? What will this be used for? What does this add?

Comments for discussion at the SLWG

(A) The data proposed is “support which the (or its agent) provides or intends to provide”. So we won’t know what support actually is provided in the baseline year 2017-18, or after the Act is implemented on 1.4.18. Nor will we know anything about service volumes. Both points are problems for monitoring the impact of the Act on demand volumes and costs.

(B) As already noted, the Carers Act will increase the number of carers who receive an assessment of their support needs. This is likely to increase demand for assistance with short breaks, and thereby the demand for replacement care for the persons they care for. More

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assessment is also likely to identify unmet need for other care services, such as home care and direct payments. We need to capture services and volumes (where possible) both for the baseline year and going forward, in order to meet the Group's remit.

DRAFT FOR CONSULTATION

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Additional data for YCS

Responsible authority/responsible local authority can be different for young carers. The responsible authority is the local authority in which the child resides (health board instead of LA for pre-school children), with some exceptions (Section 20 of the Act). Responsible local authority is the LA in which the cared-for person resides.

Variable Name	Description	Format/Values	Additional information
RespAuthority	The responsible authority for the young carer		Likely to be the same as the responsible local authority (LocalAuthority field) in most cases. Free text field, as this could potentially be a local authority, health board or school (so there are many possible options).
AppCare	The extent to which the responsible authority feels that the care provided by the young carer is appropriate.	?? (to be determined)	Carers Act S15(1)(c)

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Annex - Description of client groups

1 - Dementia

Global deterioration of intellectual functioning. Normally a progressive condition resulting in cognitive impairment ranging from some memory loss and confusion to complete dependence on others for all aspects of personal care. Exclude confusion due to other causes e.g. medicines, severe depression. Does not have to have been medically diagnosed.

2 - Mental Health Problems

Mental health problems are characterised by one or more symptoms including: disturbance of mood (e.g. depression, anxiety), delusions, hallucinations, disorder of thought, sustained or repeated irrational behaviour.
Include: persons assessed as having mental health problems whether or not the symptoms are being controlled by medical treatment.
Exclude: alcohol or drug related problems; dementia.

3 - Learning Disability

A significant, lifelong condition which has three facets: 1) significant impairment of intellectual functioning resulting in a reduced ability to understand new or complex information; 2) significant impairment of adaptive/social functioning resulting in a reduced ability to cope independently; and 3) which started before adulthood with a lasting effect on the individual's development.

4 - Physical Disability

Physical disabilities have many causes in chronic illness, accidents, and impaired function of the nervous system, which, in particular physical or social environments, result in long term difficulties in mobility, hand function, personal care, other physical activities, communication, and participation.

Include: visual impairment, hearing impairment, severe epilepsy; limb loss; severe arthritis; diseases of the circulatory system (including heart disease); diseases of the central nervous system (e.g. strokes, multiple sclerosis, cerebral palsy, spina bifida and paraplegia).

Visual impairment. Blindness or partial sightedness (unless problems resolved by spectacles or contact lenses).

Hearing impairment. Profound or partial deafness and other difficulties in hearing (unless problems resolved by a hearing aid).

Exclude: Acquired brain injury (code as 98); Problems arising from infirmity due to age (code as 8)

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5 - Addiction

Alcohol-related problems - Any person who experiences social, psychological, physical, or legal problems related to intoxication and/or regular excessive consumption and/or dependence as a consequence of his/her use of alcohol.

Drugs-related problems - Any person who experiences social, psychological, physical or legal problems related to intoxication and/or regular excessive consumption and/or dependence as a consequence of his/her use of drugs or chemical substances.

6 - Palliative care (as defined by the World Health Organisation)

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. See <http://www.who.int/cancer/palliative/definition/en/> for full definition.

8 - Problems arising from infirmity due to age

This category should only be used for clients aged 65 and over.

98 - Other vulnerable groups

Clients should be included in this client group if they do not fall under the other categories for example clients with HIV/AIDS.

Acquired brain injury - Multiple disabilities acquired after birth arising from damage to the brain through head injury, stroke, lack of oxygen, infection, or other causes. People with an acquired brain injury usually have a complex mixture of physical, cognitive, emotional, and behavioural, disorders or difficulties. This may affect how the person perceives the world and their abilities to remember, concentrate, reason and judge. The person's emotional state may be disturbed; personality, behaviour, communication and relationships are also frequently altered. Mobility, sensation, vision, hearing and balance, smell and taste, respiration, heartbeat, and bowel and bladder control may also be affected.

99 - Not known

If it is not known whether the person has been given a client group.