

What's the Story? Using National Carer Data to Develop your Narrative for CQC Assurance

Wednesday 08 November 2023 – 11:00 – 12:30PM

Partners in Care and Health

The **Local Government Association** and **Association of Directors of Adult Social Services** are **Partners in Care and Health (PCH)** working with well-respected organisations.

PCH helps councils to improve the way they deliver adult social care and public health services and helps Government understand the challenges faced by the sector.

The programme is a trusted network for developing and sharing best practice, developing tools and techniques, providing support and building connections.

It is funded by Government and offered to councils without charge.

www.local.gov.uk/PCH

Unpaid Care: Census 2021

Sarah Eley, Senior Social Care Analyst
Office for National Statistics
November 2023

Census 2021 Question

Do you look after, or give any help or support to, anyone because they have long-term physical or mental health conditions or illnesses, or problems related to old age?

Exclude anything you do as part of your paid employment

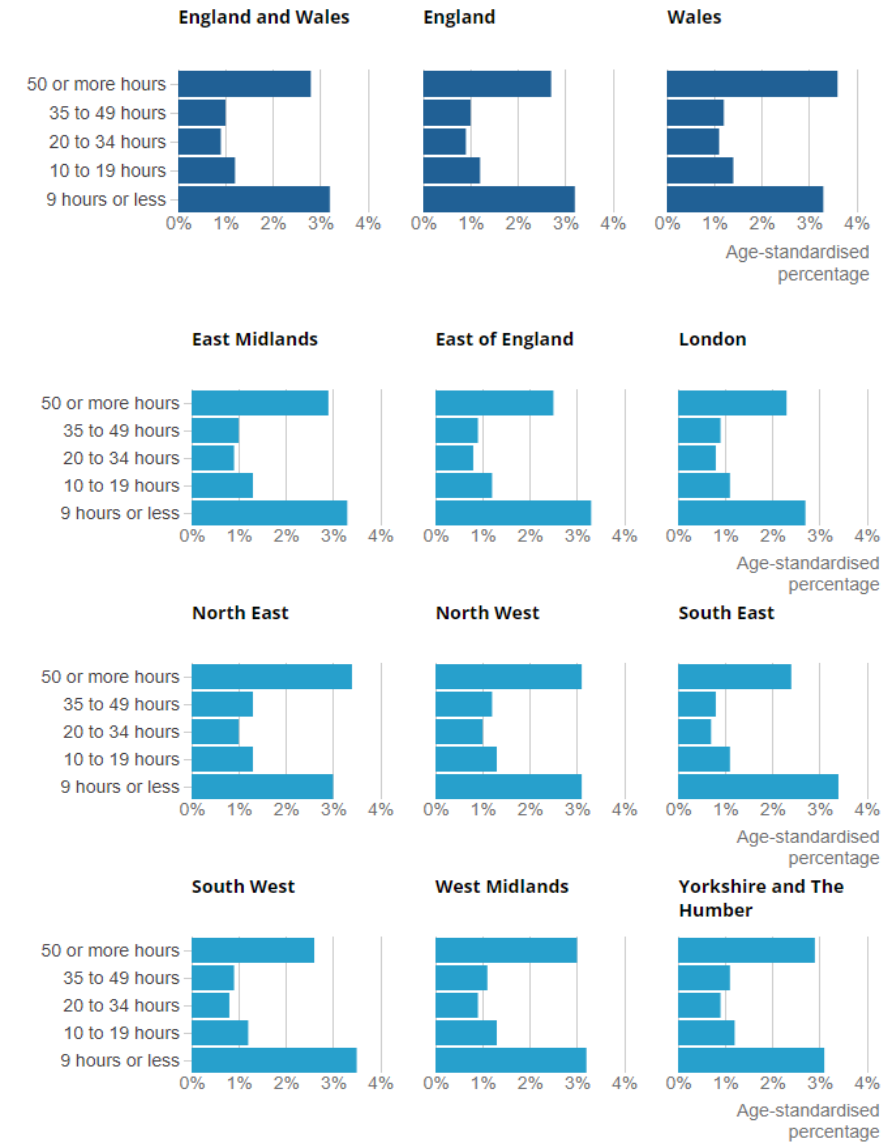
- No
- Yes, 9 hours a week or less
- Yes, 10 to 19 hours a week
- Yes, 20 to 34 hours a week
- Yes, 35 to 49 hours a week
- Yes, 50 or more hours a week

Age-standardised percentages

- % throughout are age-standardised
- Health, disability and unpaid care, are all closely related to the age of a population
- Age-standardised proportions take into consideration both population size and age-structure
- Age-standardised percentages allow us to compare over time and across different geographic areas

Key findings

- 4.7 million unpaid carers in England and approximately 310,000 unpaid carers in Wales
- Age-standardised this equates to 8.9% and 10.5% of the usual resident population, aged 5 years and over, in each country, respectively
- In England, the region with the highest percentage of people providing unpaid care was the North East (10.1%) and the region with the lowest percentage was London (7.8%)



Key findings

- There were approximately 120,000 young unpaid carers (aged between 5 and 17 years) in England (1.4% of 5- to 17-year-olds) and 8,200 in Wales (1.8% of 5- to 17-year-olds).
- There was a higher percentage of people providing unpaid care in the most deprived areas in England and Wales (10.1% and 11.5% respectively) compared with the least deprived areas, which had the lowest percentage of people providing unpaid care in both England and Wales (8.1% and 9.7%, respectively).

England

	Most deprived										Least deprived									
	1	2	3	4	5	6	7	8	9	10	1	2	3	4	5	6	7	8	9	10
9 hours or less	2.1	2.4	2.7	2.9	3.2	3.4	3.5	3.6	3.7	3.9	2.1	2.4	2.7	2.9	3.2	3.4	3.5	3.6	3.7	3.9
10 to 19 hours	1.2	1.2	1.2	1.2	1.2	1.2	1.2	1.2	1.2	1.1	1.2	1.2	1.2	1.2	1.2	1.2	1.2	1.2	1.2	1.1
20 to 34 hours	1.2	1.1	1.0	0.9	0.9	0.8	0.8	0.7	0.7	0.6	1.2	1.1	1.0	0.9	0.9	0.8	0.8	0.7	0.7	0.6
35 to 49 hours	1.6	1.3	1.2	1.0	0.9	0.9	0.8	0.7	0.7	0.6	1.6	1.3	1.2	1.0	0.9	0.9	0.8	0.7	0.7	0.6
50 or more hours	4.0	3.5	3.1	2.8	2.7	2.5	2.4	2.3	2.1	1.9	4.0	3.5	3.1	2.8	2.7	2.5	2.4	2.3	2.1	1.9

Age-standardised percentage (%)

Wales

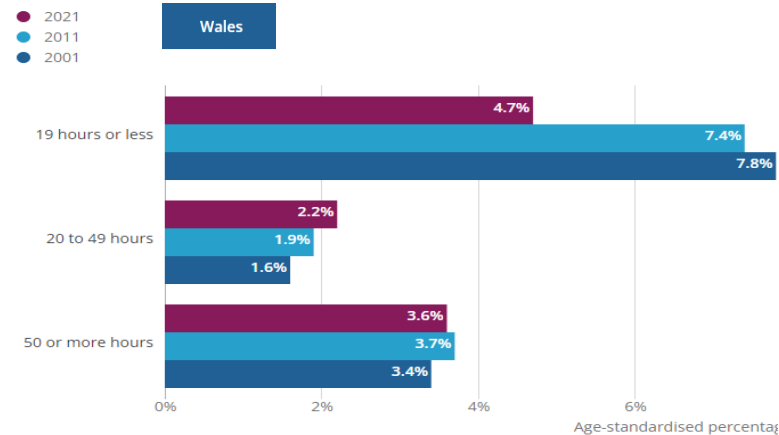
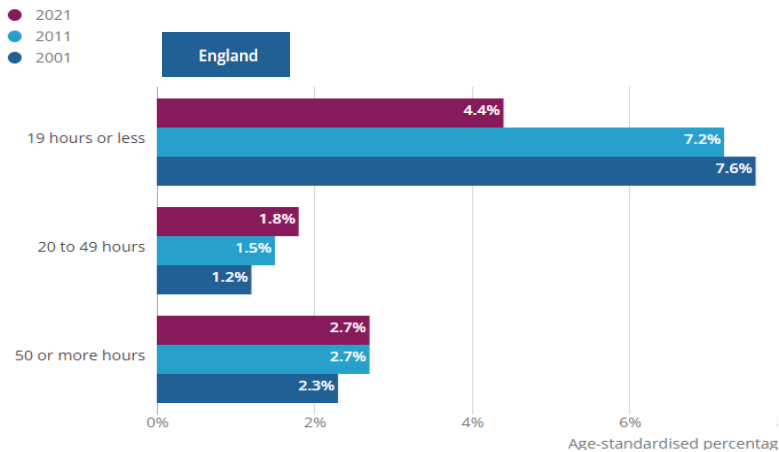
	Most deprived					Least deprived				
	1	2	3	4	5	1	2	3	4	5
9 hours or less	2.4	3.0	3.3	3.6	3.9	2.4	3.0	3.3	3.6	3.9
10 to 19 hours	1.4	1.5	1.5	1.4	1.4	1.4	1.5	1.5	1.4	1.4
20 to 34 hours	1.2	1.2	1.0	0.9	0.9	1.2	1.2	1.0	0.9	0.9
35 to 49 hours	1.7	1.3	1.1	1.0	0.8	1.7	1.3	1.1	1.0	0.8
50 or more hours	4.8	4.1	3.5	3.0	2.7	4.8	4.1	3.5	3.0	2.7

Age-standardised percentage (%)

Comparisons to previous years

- There was a decrease in the percentage of people reporting to provide unpaid care in 2021 compared with the 2011 Census in England and Wales across most age groups
- In England and Wales an estimated 5.0 million usual residents aged 5 years and over provided unpaid care in 2021, this is an ASP of 9.0%, a decrease from 11.4% in 2011.

Reasons for the decrease in 2021



Potential explanations for changes in the provision of unpaid care could include:

- We've seen an improvement in very good health and a decline in disability, this could have led to a reduction in the need for unpaid care
- Coronavirus guidance on reducing travel and limiting visits to people from other households
- Unpaid carers who previously shared caring responsibilities may have taken on all aspects of unpaid care because of rules on household mixing during the coronavirus pandemic. Evidence for this is in the increased hours of unpaid care at an individual level
- Deaths were highest in the older population and peaked at the beginning of 2021, this could have led to a reduction in the need for unpaid care
- Changes in the question wording between 2011 and 2021 may have had an impact on the number of people who self-reported as unpaid carers

**Introducing the Census 2021
custom dataset tool.**

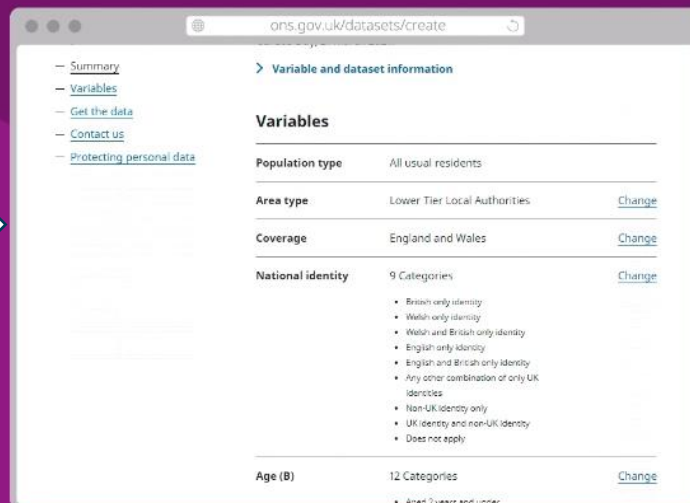
**Create millions of combinations
of Census 2021 results to suit
your needs.**



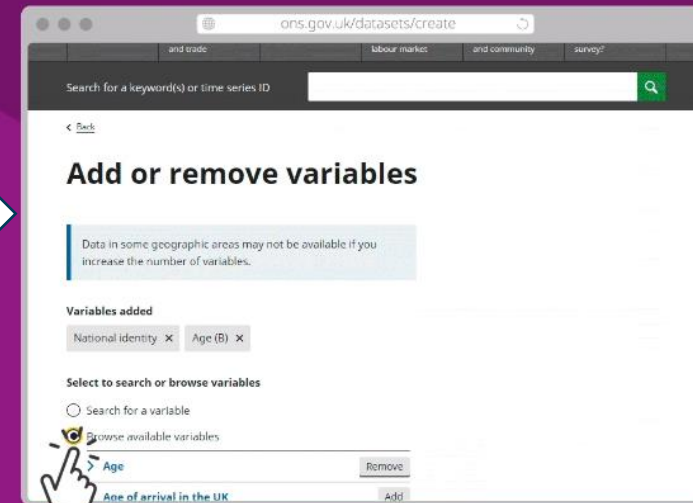
Select 'Create a custom dataset' to **start from scratch** or 'Get census data' to begin with an **existing dataset**.



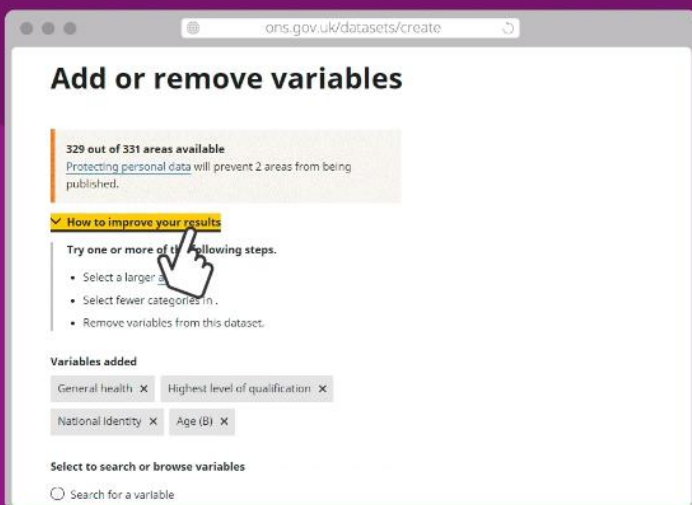
You can customise the **area type** and **coverage**.



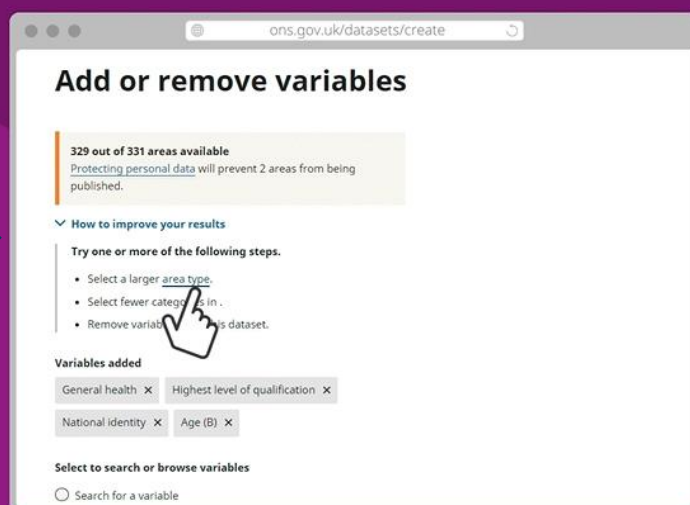
Then, **add variables** you're interested in and select **how many categories** you want.



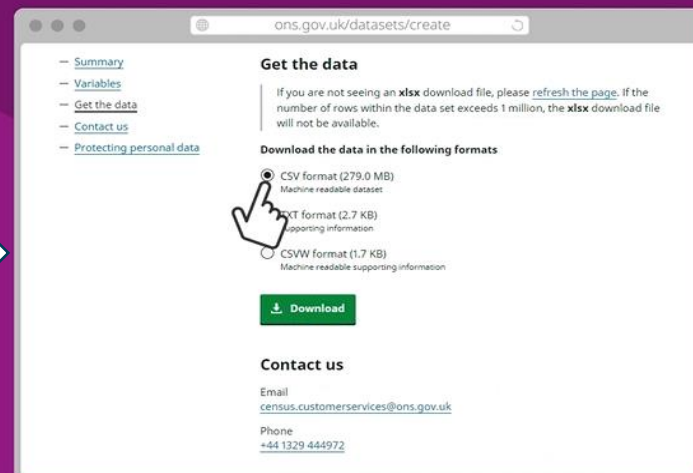
The data are **secure**, so you can't personally identify anyone. This means the datasets may not contain as much detail as you might need...



...so we'll suggest ways to **improve your results**.



Get data. No fuss.



Releases to date

- Topic summary; [Unpaid care, England and Wales: Census 2021](#)
The number of usual residents aged 5 years and over who provide unpaid care, and how many hours they provide in a typical week, Census 2021 data.
- [Unpaid care by age, sex and deprivation](#), England and Wales: Census 2021
The provision of unpaid care at country, regional and local authority level and analysis on deprivation with comparisons to Census 2001 and 2011.
- [Unpaid care and protected characteristics](#), England and Wales: Census 2021
The provision of unpaid care by protected characteristics across England and Wales, with comparisons with the 2011 Census.
- [Census maps](#)
Interactive map tool that visualises Census 2021 data on different topics down to a local authority area and neighbourhood level.
- [Custom dataset](#)
Make your own datasets combining variable

Carers UK: Research with unpaid carers

Melanie Crew

Senior Research and Policy Officer - Carers UK

What is the State of Caring survey?

- **Annual survey** with unpaid carers
- **High response rate** – 11,667 carers took part in 2023
- **Carers asked about a range of topics** – finances, health, employment
- **Repeat questions from previous years as well as new questions on topical issues**
- **Carers help develop the survey**
- **Mix of qualitative and quantitative questions**

Outputs from this year's survey

- **Two reports published – finances (Oct) and health (Nov)**

<https://www.carersuk.org/policy-and-research/state-of-caring-survey/>



- Report on **caring and employment published on Carers Rights Day**
23 Nov

Impact of caring on finances

- **Carers are struggling even more with their finances** – 30% struggling to make ends meet (27% in 2022)
- **Carers are cutting back more** - 34% had cut back on essentials (eg food or heating) compared to 25% in 2022 and 13% in 2021.
- 60% worried about the **impact of caring responsibilities on their finances.**
- 62% finding it more difficult to manage financially due to the **increase in the cost of living.**

Impact of caring on finances

Carers in receipt of Carer's Allowance are struggling even more.

- 45% of carers receiving Carer's Allowance are struggling to make ends meet
- 71% of carers in receipt of Carer's Allowance said they are worried about living costs and whether they can manage in the future
- 34% of carers in receipt of Carer's Allowance were struggling to afford the cost of food - an increase from 29% last year

Impact of caring on health

- 82% of carers said the **impact of caring on their physical and mental health would be a challenge** over the coming year
- A significant proportion of carers said their **mental health has been affected by caring:**
 - 79% feel stressed
 - 50% feel lonely
 - 49% feel depressed
- 54% of carers said their **physical health had suffered**, and 22% said that caring had caused them **injuries**

Impact of caring on health

- 61% of carers said they **needed more support** to be able to look after their health and wellbeing.
 - 42% needed more support from NHS or healthcare professionals
 - 50% being supported by family and friends – compared to 37% being supported by social care services and 19% being supported by health services
- 44% had **put off health treatment** because of their caring role.
- 78% agreed they were **worried about being unable to provide care in the future.**

Impact of caring on health

Carers with poor mental health are struggling even more.

- Over a quarter of carers (27%) said their **mental health was bad or very bad.**
- 39% of carers whose mental health was bad or very bad said they were **not receiving any support** with their mental health.
- Nearly three quarters (73%) of carers whose mental health was bad or very bad said that they continued providing care even though they **felt they were at breaking point.**

- **New analysis of State of Caring data by region**
- **Bespoke reports**
- Focusing on key themes including **health and support with caring**
- **Mix of quantitative and qualitative data**
- **Analysis of responses over time**

- Understanding **carers' needs at a regional level**
- Using State of Caring regional analysis when **preparing for CQC assessments**
- **State of Caring data used alongside other resources – PCH toolkit**

<https://www.local.gov.uk/our-support/partners-care-and-health/cqcs-new-assurance-framework/unpaid-carers-and-care-quality>



Carer Data and CQC Assurance

Carers Trust Network Data Exchange

Andrew Russell

UK Social Impact Team

What is the Network Data Exchange (NDE)?

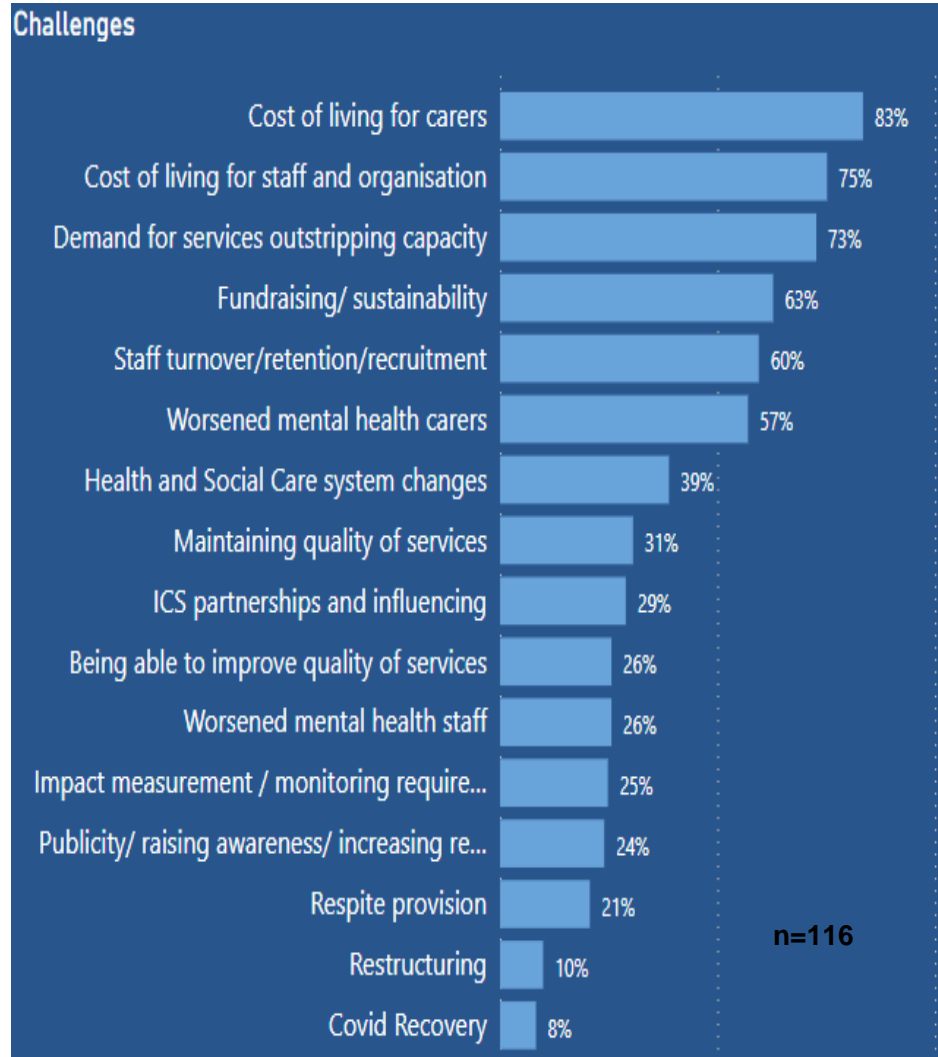
- Carers Trust – an infrastructure charity supporting and representing a network of **120-130** local carers organisations
- These are the third-sector organisations delivering support to carers
- Covering England, Scotland, Wales; 85% of Local Authorities
- Every year we survey them about finances, challenges, carer numbers and demographics

Survey Caveats

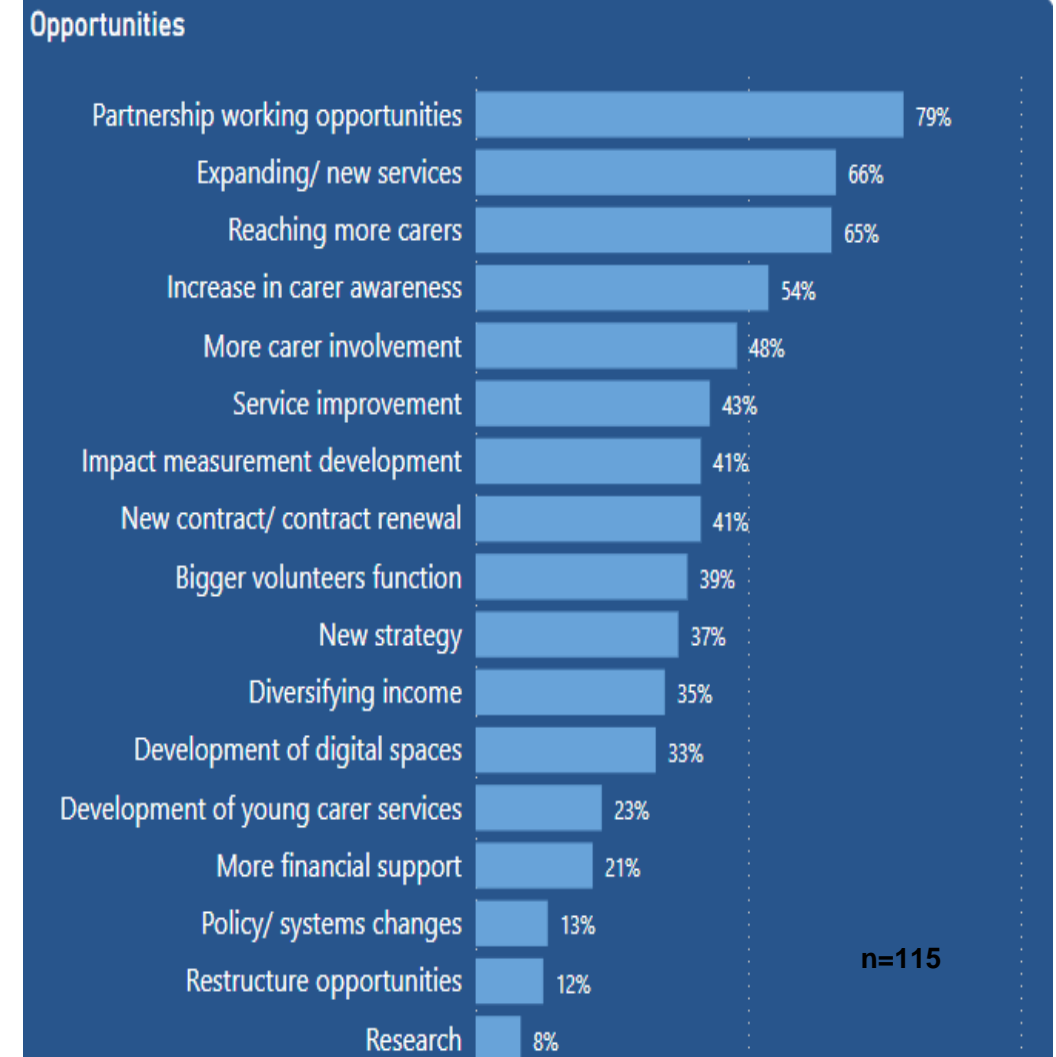
- **Survey of our Network, not all local carer organisations:** still likely to be reflect ground truth for all, but technically not a representative sample.
- **Missing data:** We do not get 100% response rate; demographic data does show gaps
- **Annual survey:** data is not refreshed throughout the year

What we are hearing: Sustainability is a challenge

Network Partner Challenges



Network Partner Opportunities



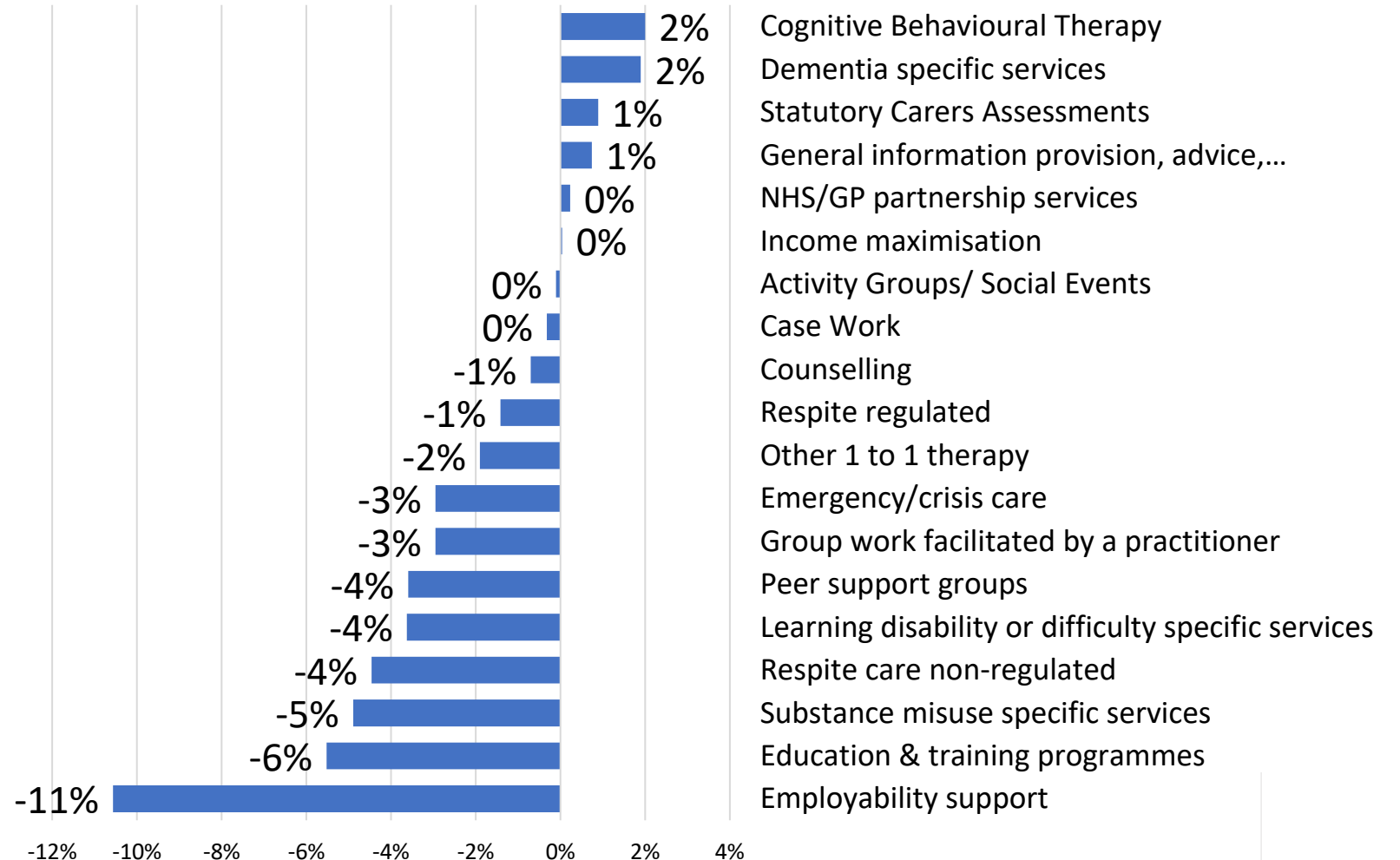
What we are hearing: The provision of most services is decreasing

Employability support is the service NPs are most interested in, and also the service that has decreased the most in provision.

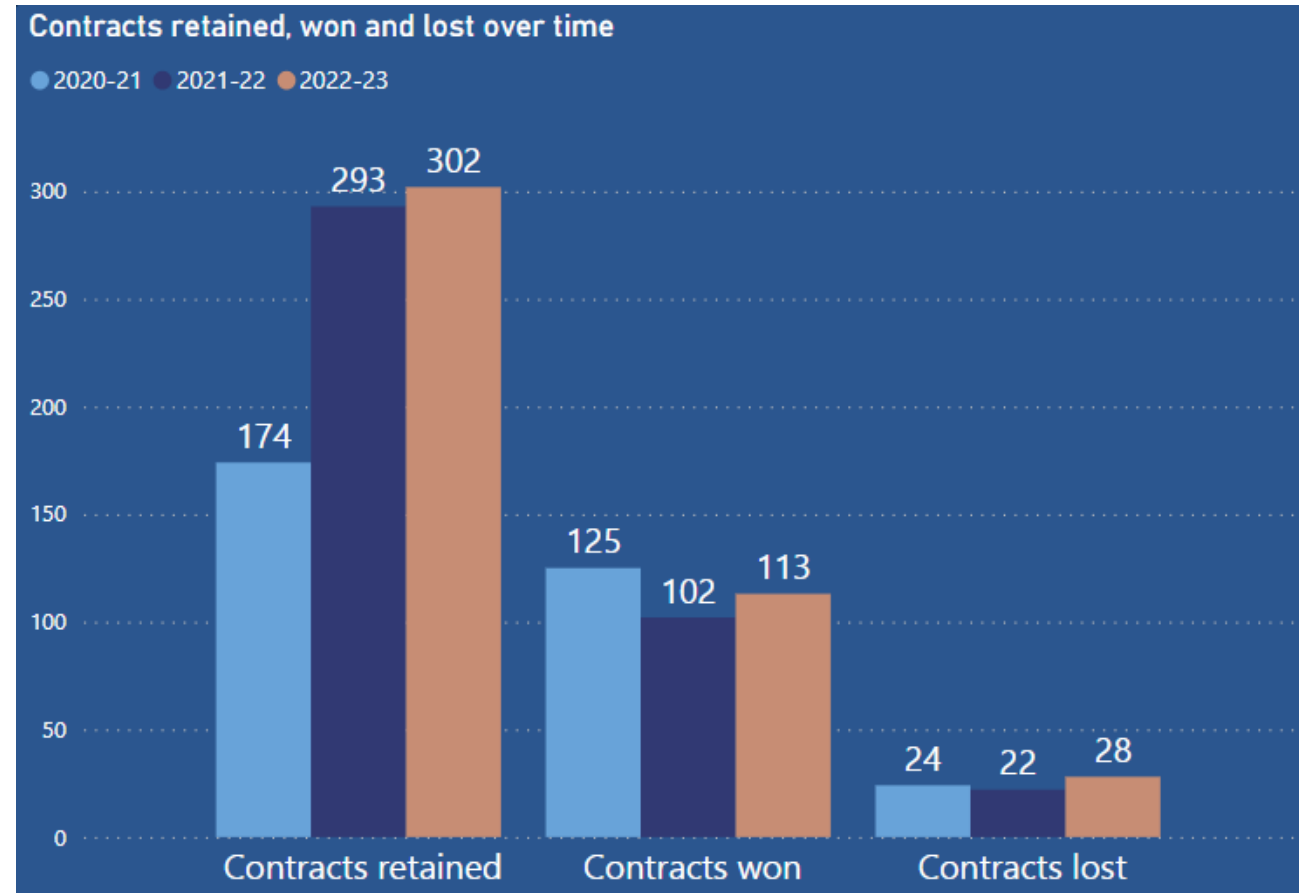
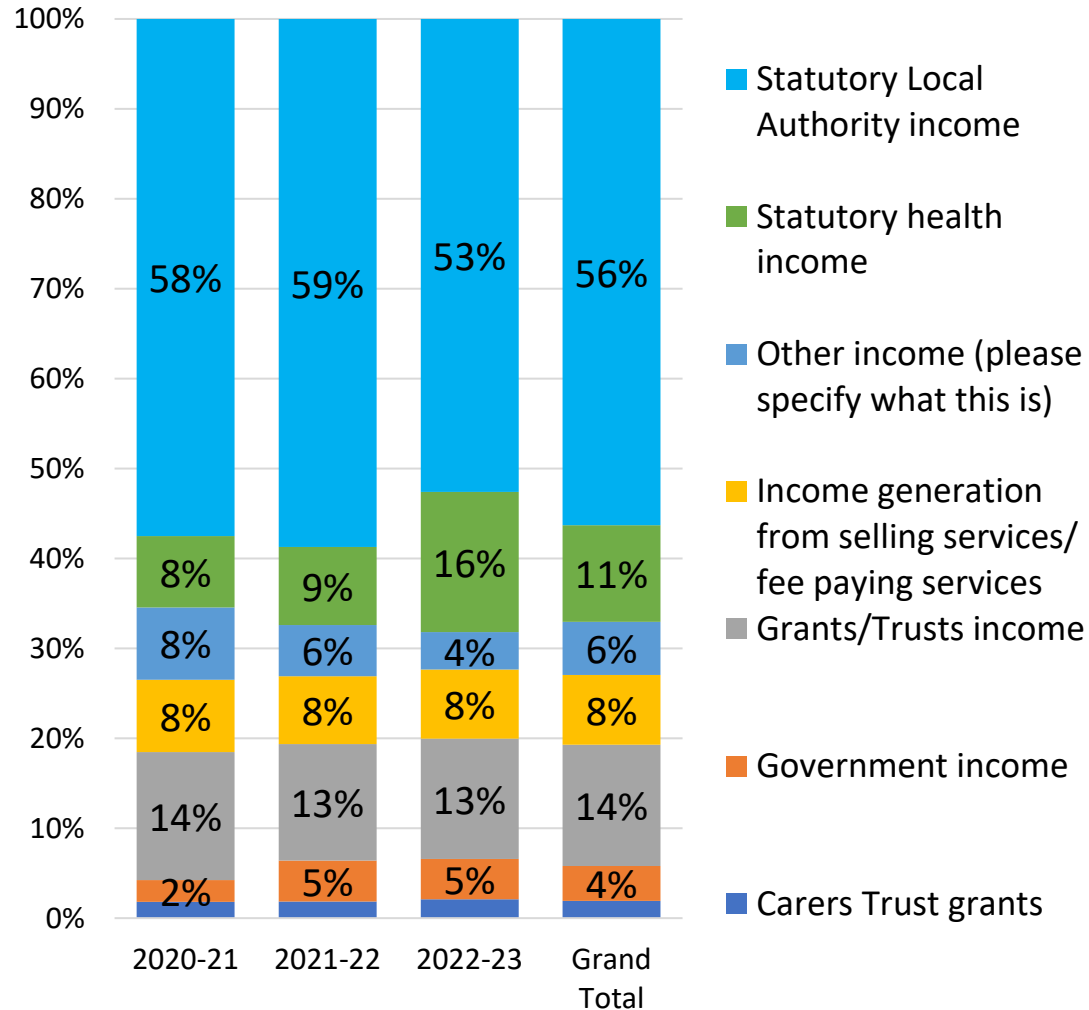
Interest in income maximisation support has gone down, and there hasn't been an increase in the provision of these services.

CBT and dementia services provision have increased the most and interest remains high but slightly lower than last year.

Percentage of the Network providing services change from last year



What we are hearing: Income reliant on statutory funding



Carers Trust Network Data Exchange – what it means for you

Report on Carers Trust website.

[Carers Trust's 2023 Network Data Exchange results - Carers Trust](#)

Data available by Nation and Region. Use it to understand:

- the environment local carers organisations are working in;
- the scale of their work;
- who they are reaching and who they are not;
- what services are available and which are closing.



Adult Social Care: Unpaid Carers

The current picture and future data developments

Dave Boath, PCH Research & Data

The current picture: 2022/23 Carers Data

England Total	2021/22	2022/23	Change
Total Carers Supported during the year	380,725	356,235	-6.4%
Carer Age profile:			
Under 18	7,275	4,245	-41.6%
18 to 25	10,575	8,165	-22.8%
26 to 64	196,025	186,165	-5.0%
65 to 84	134,440	128,350	-4.5%
85 and over	32,410	29,315	-9.5%
Respite/Other Forms of Carer Support	33,300	36,200	+8.7%
Expenditure: Support to Carer	£175,708,000	£195,144,000	+11.1%



6% reduction in the total number of carers supported during the year compared to the previous year
The reduction was more pronounced for young carers and young adult carers (42% and 23% respectively)

9% increase in Respite, suggesting that more carers have been able to have a break in the last 12 months.



Spending on Carers has increased by 11%, some of which can be explained by inflationary pressures
On average the spend per carer supported has increased
Spend on carers remains approximately 1% of the Total Adult Social Care spend.



Adult Social Care – Client Level Data (ASC-CLD)

<https://www.ardengemcsu.nhs.uk/adult-social-care-client-level-data/>

New quarterly mandated collection for 2023/34 which replaces the annual aggregate SALT activity collection
A person level collection detailing events for every adult and carer interaction with Adult Social Care

What does this mean for carers?

Greater parity on the collection of adult and carer data. More detailed information for local and national decision making

What is being collected for Carers?

Personal information	gender, age, ethnicity, sensory, postcode, accommodation & employment
NHS ID	validated to link to NHS records in the future
Carer specific	hours caring, multiple carer and cared for relationships
Contacts	contact source, the intended next step, start & end dates
Assessments	type (carer or joint), eligibility, what was the outcome, start & end dates
Services	specific carer service types, costs of packages, unit costs for carers
Reviews	planned/unplanned, the intended next step, review outcomes achieved



Local authority data on Carers is less developed than for adults, and many councils commission external carer organisations to deliver services which makes data sharing and reporting more challenging

Linked health and care data will give a partial view; for adults and carers who are known to both the NHS and ASC.

Work with the system to develop and test a new Carers report on LG Inform bringing together a range of data sources and resources that is:

Interactive and bespoke for each council area, with the option to change the comparison group for benchmarking purposes

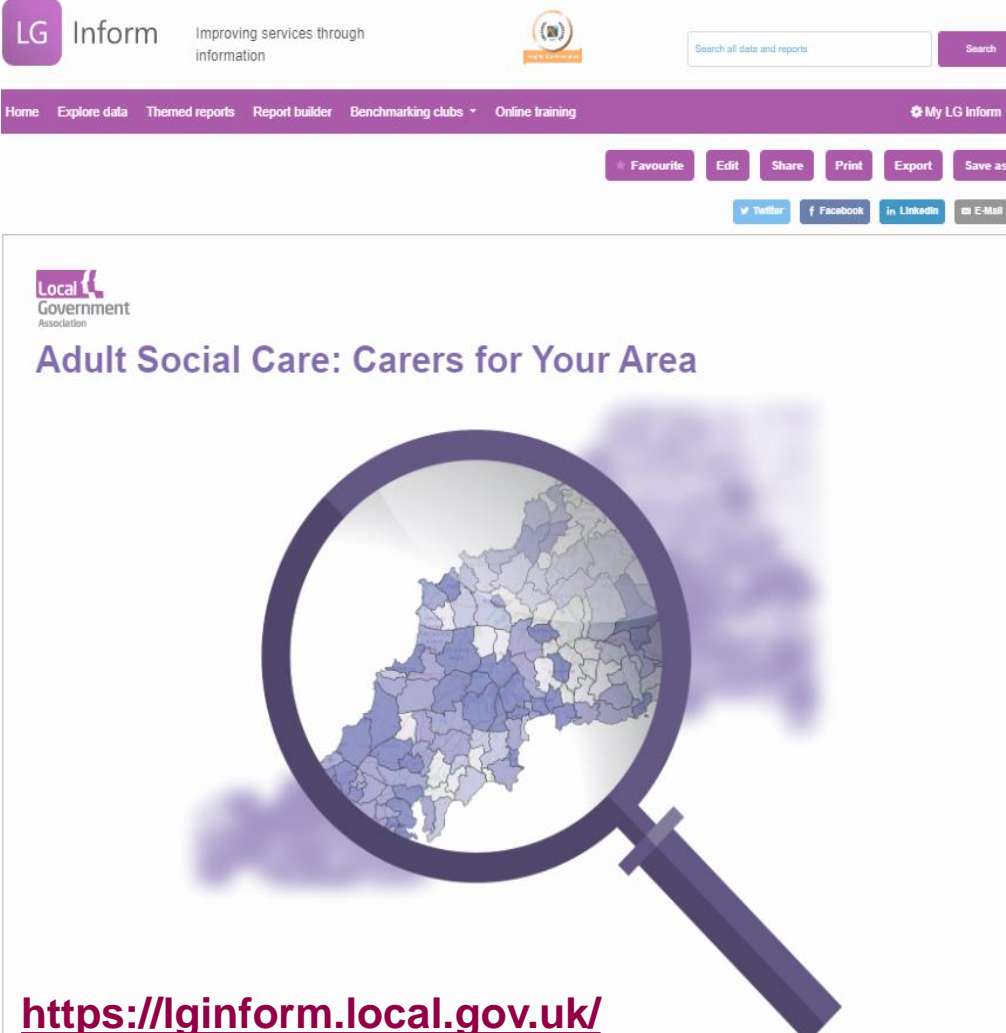
Data Scoping

- ONS Census – Carer Population Profiles
- DWP - Carer Employment and benefits
- GP - Carer registrations and patient survey
- SALT - Adult Social Care Carers Activity
- Carer experience inc. SACE Survey, Carers UK, Carers Trust
- Adult Social Care Expenditure on Carers (ASC-FR)
- Adult Social Care Outcomes Framework (ASCOF) Carers measures

...to include Carer summaries from Client Level Data when available

Anything else?

What story do you want to tell?



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Search all data and reports Search

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Local Government Association

Adult Social Care: Carers for Your Area

<https://lginform.local.gov.uk/>

Free to sign up for gov.uk domains

Questions and Discussions

Reflections, gaps and challenges

**Simon Bottery, Senior Fellow
Social Care at The Kings Fund**

Thank You