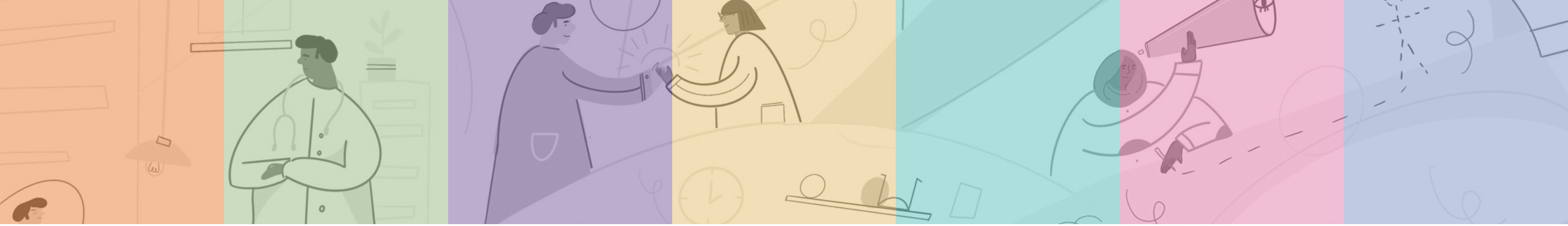

EXPLORING THE CARERS CENSUS

Discovery Report

NHS
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Design
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Improvement
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CONTENTS

KEY LEARNING & OPPORTUNTIES FOR EACH THEME IDENTIFIED:

INTRODUCTION

The Carers Census aims to help monitor the implementation of The Carers Scotland Act (2016) and identify if the Act is making a difference to the lives of carers across Scotland. The census collects a variety of information on unpaid carers, and the support they are provided with. Data is collected annually from across Scotland via Health and Social Care Partnerships (HSCPs) and local carer organisations.

There continues to be significant gaps in data about unpaid carers in Scotland with the recent Carers Census report highlighting challenges around quality and variance of data being submitted from local areas. Concerns had also been raised that the requirement for data has impacted on local assessment practice and the experience of staff and carers.

In undertaking this discovery project we wanted to further understand these challenges.

About this report

During this discovery project we hosted a number of events and interviews with key stakeholders, with participation from over 130 staff and carers representing 30 local authority areas in Scotland.

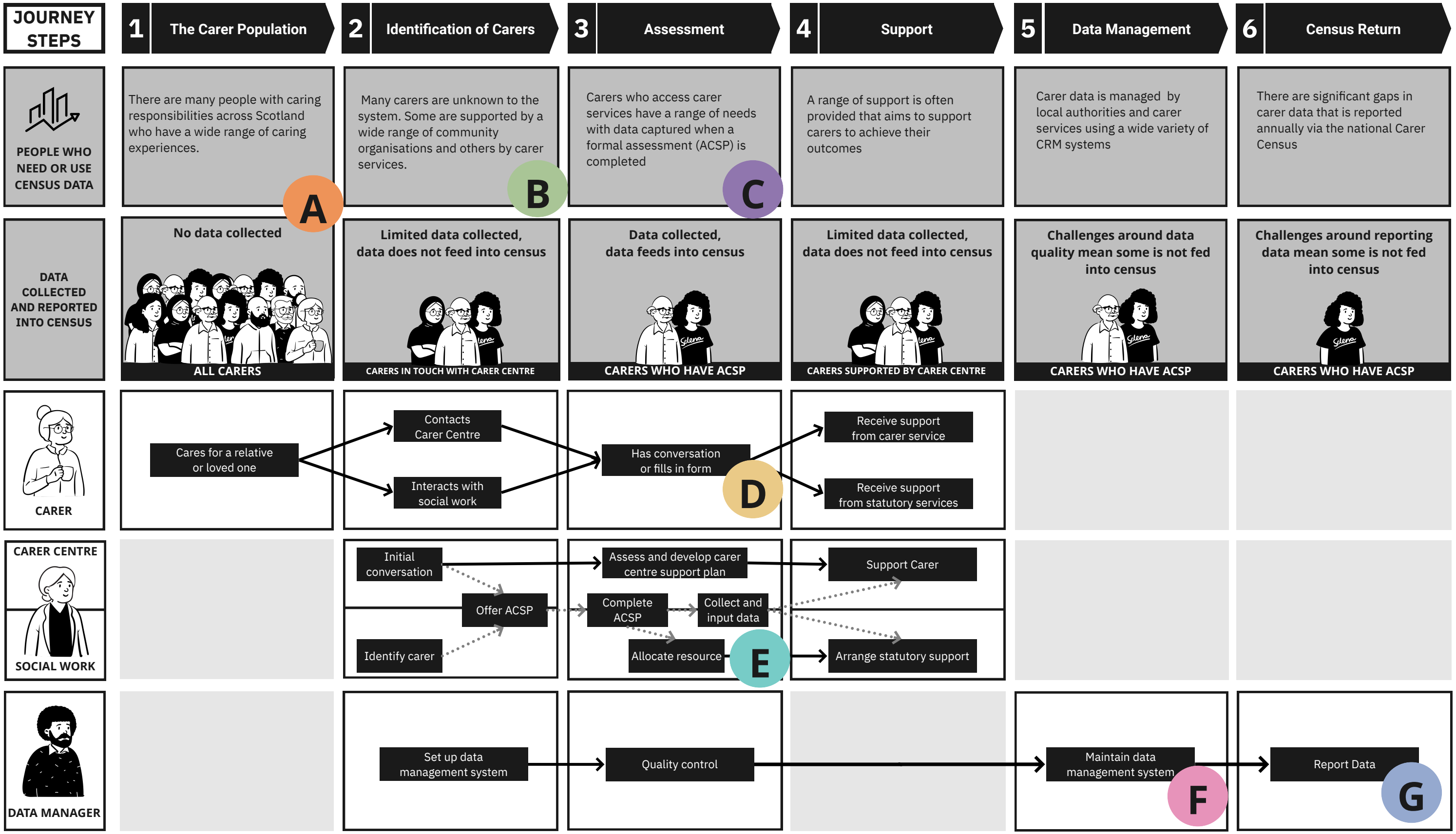
Participants shared their current experience of how carer data is collected and managed locally and reported via the national Carers Census, including the key challenges and opportunities for improvement.

This information was used to create a staff and carer experience map which identified 7 key themes regarding the design and implementation of the Carers Census. In this report we explore each theme in turn by highlighting the key learning and observations from across the discovery activity, quotes from participants and opportunities for improvement.

This report is intended to be used as a discussion tool for all stakeholders to identify next steps in improving the design and delivery of the Carers Census.

EXPERIENCE MAP

* ACSP = Adult Carer Support Plan



JOURNEY STEPS	1 The Carer Population	2 Identification of Carers	3 Assessment	4 Support	5 Data Management	6 Census Return
PEOPLE WHO NEED OR USE CENSUS DATA	There are many people with caring responsibilities across Scotland who have a wide range of caring experiences. A	Many carers are unknown to the system. Some are supported by a wide range of community organisations and others by carer services. B	Carers who access carer services have a range of needs with data captured when a formal assessment (ACSP) is completed C	A range of support is often provided that aims to support carers to achieve their outcomes	Carer data is managed by local authorities and carer services using a wide variety of CRM systems	There are significant gaps in carer data that is reported annually via the national Carer Census
DATA COLLECTED AND REPORTED INTO CENSUS	No data collected ALL CARERS	Limited data collected, data does not feed into census CARERS IN TOUCH WITH CARER CENTRE	Data collected, data feeds into census CARERS WHO HAVE ACSP	Limited data collected, data does not feed into census CARERS SUPPORTED BY CARER CENTRE	Challenges around data quality mean some is not fed into census CARERS WHO HAVE ACSP	Challenges around reporting data mean some is not fed into census CARERS WHO HAVE ACSP
CARER	Cares for a relative or loved one	Contacts Carer Centre Interacts with social work	Has conversation or fills in form D	Receive support from carer service Receive support from statutory services		
CARER CENTRE SOCIAL WORK		Initial conversation Offer ACSP Identify carer	Assess and develop carer centre support plan Complete ACSP Collect and input data Allocate resource E	Support Carer Arrange statutory support		
DATA MANAGER		Set up data management system	Quality control		Maintain data management system F	Report Data G

KEY THEMES

DESIGN OF THE CENSUS

The purpose of the census and what it is aiming to measure.

A. There is a wide range of expectation regarding the purpose of the Carers Census

B. Data is captured on a small section of the unpaid carer population in Scotland

C. The current dataset limits the number of carers included and the quality of data collected

DELIVERY OF THE CENSUS

Implementation and impact of data requirements on assessment and data management practices for carers and staff.

D. Assessments currently don't always add value for carers

E. There is a risk that data requirements negatively impact on assessment practice

F. Data management systems require significant resource to implement and maintain

G. The national census reporting process does not align with local systems

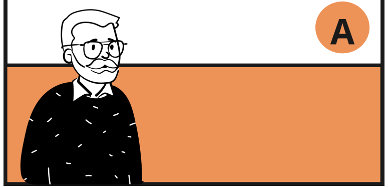
CARER PERSONAS

We interviewed 20 carers from across Scotland. Based on our insights from these interviews, we developed a set of personas. They highlight the caring roles and wide range of experiences of carers which are currently not always captured in census data.

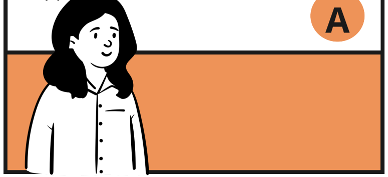
Participants lived in East Lothian, Highlands, Lanarkshire, Moray, and the Western Isles. They cared for their child, spouse or partner, parent, sibling, or more than one family member. They had been in their caring role for up to 20 years. Some had experience of assessment with social work or via a carers centre.

The personas provide additional context to the key themes discussed in this report, and we have marked which one they correspond to.

I care for both parents who have dementia – my mum for 8 years and my dad for 2 – and my mother in law with Parkinson's. It got to the stage it was too much and my doctor signed me off work – I feel I need to do normal things and not be a carer all the time. When it came to the crunch I had to cut my hours and take carers allowance – I've lost money but I had to take it. My mum won't let the carers in to do her shower, it's really stressful, I was there for two and a half hours today on my day off. It's a huge commitment going in every day. My husband doesn't mean to but he makes me feel guilty.



I'm the main carer for my 12 year old son. I'm responsible for meeting all his needs and coordinating all his support. If I don't chase things up nothing seems to happen, I'm always the one in the background pushing things forward. My family makes me feel empowered and good about myself but outside I feel like a burden that I'm not contributing anything to society. I feel isolated as my son's condition is rare, it's difficult to find advice and there's no peer group to connect with. I also worry about my husband as there's a lot of stress on him and men don't talk about their problems. My daughter is a young carer. Everything has always been about my son and I've never felt my needs are part of the equation but I've recently started reaching out for support.



1 THE CARER POPULATION

A There is a wide range of expectation regarding the purpose of the Carers Census

The purpose of the Carers Census is stated as evaluating the impact of the Carers Act, however stakeholders have much broader expectations.

Key Learning

Purpose of the Carers Census includes
- To monitor impact and implementation of the Carers Act
- To provide deeper understanding of local carer demographics (caring situations and needs)
- To capture information on the range and impact of support being accessed by carers
- To support planning and commissioning of services (national and local)

Opportunity

- To work in collaboration with national and local stakeholders to create a shared purpose for the Carers Census that meets national and local needs

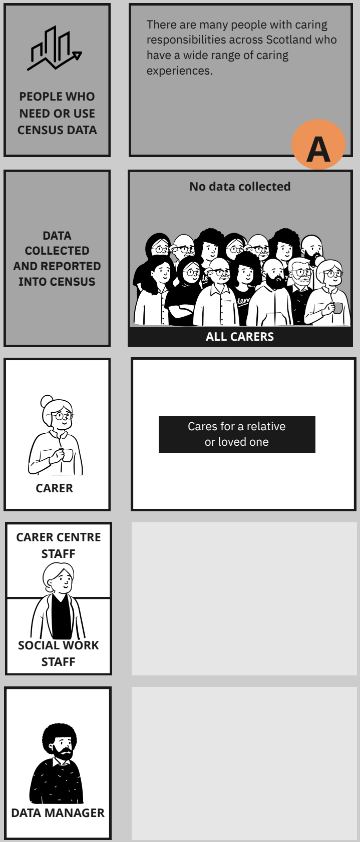
What workshop participants said:

"Deeper understanding of diversity of carers across Scotland."

"Finding out more about the situations, challenges, and issues faced by carers in Scotland to inform support."

"To capture the current unpaid carer landscape and help inform what needs to happen to better support unpaid carers (and by definition cared for people) moving forwards."

"Purpose leading to recording of unmet need to support service provision and design."



1 THE CARER POPULATION

A

There is a wide range of expectation regarding the purpose of the Carers Census

Other observations

- Recognition of the importance of data and the current limitations with the Carers Census due to poor data quality, variation etc and the opportunity for improvement
- There is potential for the Carers Census to impact across a wider range of stakeholders and services e.g. to shape learning /decision making for wider services, not just carer services
- Importance of Carers Census data being available for each local area and not just providing a national picture
- Communication about the Carers Census is challenging without a clear purpose and impacts on participation

Opportunities

- To increase visibility of the Carers Census to influence a wider range of stakeholders across the system
- To identify current barriers and enablers to ensure future capacity for local breakdown of census data
- To develop a clear communications tool on the purpose and aims of the Carers Census and how the information will be used for all participating

What workshop participants said:

> “Data needs to be more accurate for anyone to benefit.”

> "Having a data source that is accessible to other organisations and people who might not realise how important this is. Sharing on a wider scale and building the evidence."

> "Do people understand what it is for? If that backstory isn't there doesn't encourage people to complete."

> “If available in a locality breakdown, could be used to inform local strategies and commissioners."

PEOPLE WHO NEED OR USE CENSUS DATA

There are many people with caring responsibilities across Scotland who have a wide range of caring experiences.

A

DATA COLLECTED AND REPORTED INTO CENSUS

No data collected

ALL CARERS

CARER

Cares for a relative or loved one

CARER CENTRE STAFF

SOCIAL WORK STAFF

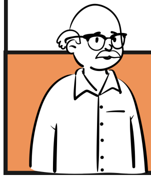
DATA MANAGER

1 THE CARER POPULATION: PERSONAS

I support my 94 year old mum who lives 8 minutes away. I have to check in on her every day, do little tasks, take her to appointments but my mum manages her own personal care and makes her own meals. My siblings recognise me as mum's carer and really appreciate that my husband and I have taken on this responsibility. I'm pleased to have the opportunity to care for my mum as she has done so much for me. The difficulty is that I can't leave her alone and go away for even a few days.

A

I care for my wife. My biggest challenges have been around getting the right care package for her – the definition of care was too narrow, it was just eating, sleeping and dressing and I've had to make complaints about the care providers when they disappear. Being a carer the challenge is how to maintain old relationships and/or create new relationships, there's a real risk of experiencing social isolation.

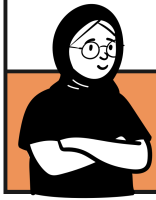


A

I've been caring for my husband for the last 20 years and now I'm also a carer for my mum. Everything has to be planned down to the last – it doesn't help that I have chronic fatigue and anxiety – I have to plan, if I don't plan I can't do it. I always feel that I'm on a balance and that balance is very unstable and they'll just be one thing that causes everything to topple. It got so bad that I rang social services in tears and when somebody came out they said 'you need to speak to this person, this person, this person' and they mentioned the carers centre. The biggest problem at the moment is the OT waiting list.

A

I look after my daughter, she's my wee miracle, I would not change her for the world. I feel isolated, it's just me and her, I need to plan everything to make sure she's safe, eating, drinking. I miss work sometimes and I miss the people. I'm constantly fighting for services for my girl. Just because I'm not working doesn't mean I'm not busy – busy with the excess washing, drying, cleaning, preparation, shopping, picking up meds. Me time is when I can get out in the garden.



A

2 IDENTIFICATION OF CARERS

B

Data is captured on a small section of the unpaid carer population in Scotland

The Carers Census is not representative of the number and diversity of carers in Scotland as only captures information on carers formally identified by carers. services

Key Learning

- Carers are supported by a wide range of services outwith HSCP/Carers Centres who do not report via the Carers Census
- Not all carers interacting with HSCP/Carers Centres will be included in the Carers Census data collection
    - Carers may not be identified during assessment of cared for person
    - Many carers do not want to formally identify/be assessed especially when support is already in place for the cared for person
    - Many carers access support via Carers Centres without completing a formal assessment so data is not captured

Opportunity

- To clearly define who we identify as an unpaid carer and include in data capture
- To develop understanding of the range of local organisations providing support for carers to ensure a more inclusive census
- To include a broader range of data providers and diversify the types of organisations providing data to reflect the wider carer population
- To work with a small number of local areas to implement a test of change around diversifying the range of data providers
- To explore how to capture information from small organisations e.g. learn from other approaches working with third sector organisations

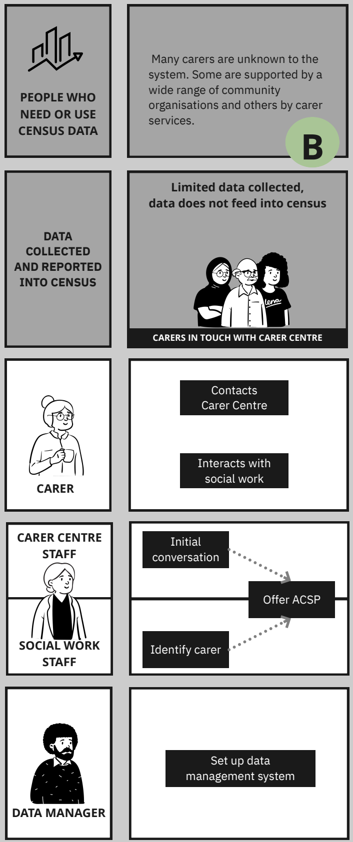
What workshop participants said:

"Census does not represent the numbers we know of so to take those figures and think we can base anything on it - drop in the ocean."

“Capturing low level support (local example of short break/sitter services). How to capture this without imposing laborious data capture process on small orgs.”

“Many other orgs funded to support unpaid carers but census not diverse enough to support data collection.”

“Some smaller third sector organisation may not have IT systems compatible with making a submission, or systems in place to capture the information during the contact they have with a carer.”



PEOPLE WHO NEED OR USE CENSUS DATA

Many carers are unknown to the system. Some are supported by a wide range of community organisations and others by carer services.

B

DATA COLLECTED AND REPORTED INTO CENSUS

Limited data collected, data does not feed into census

CARERS IN TOUCH WITH CARER CENTRE

CARER

Contacts Carer Centre

Interacts with social work

CARER CENTRE STAFF

SOCIAL WORK STAFF

Initial conversation

Offer ACSP

Identify carer

DATA MANAGER

Set up data management system

B

Data is captured on a small section of the unpaid carer population in Scotland

Other observations

- Many carers are not known to any services as often do not self identify or attempt to access support e.g. carers are not aware they are carers or do not want to recognise themselves as having this role
- There is no mandatory obligation for participation so not all areas/organisations share their data (NB: The 2020-21 collection received 54 returns covering 26 local areas, 19 from HSCPs and 35 from third sector organisations. 5 areas did not submit any return)
- Recognition of the important role of the health and social care workforce in identifying and referring carers e.g. primary care can identify carers close to the point of diagnosis of a cared for person
- Outreach work is important and successful in reaching certain carer populations e.g. working with schools to identify young carers, visiting community groups to identify BAME carers

Opportunities

- To create data collection agreements with local organisations to ensure participation with data capture and reporting
- To provide a single framework for all commissioned organisations (not just HSCPs and carer centres)

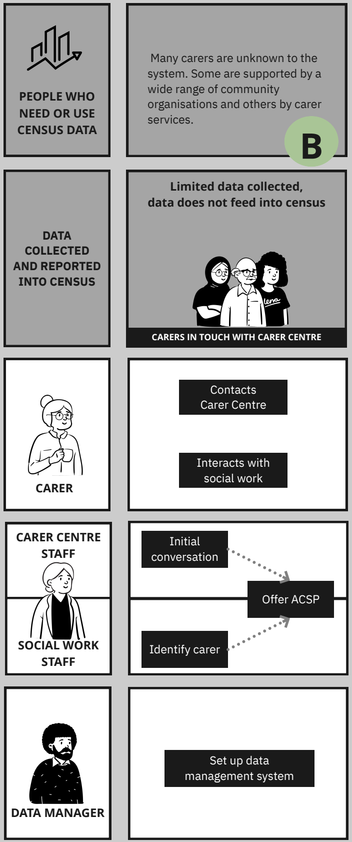
What workshop participants said:

“We are scratching the surface, how do we identify more carers?”

“Many people don’t know or identify themselves as a carer.”

"We know we have around 40,000 unpaid Carers locally, but our return captured only a small fraction of those we support either directly or indirectly."

“Currently take-up can be variable with some areas not responding – how do we encourage areas to submit their data.”



PEOPLE WHO NEED OR USE CENSUS DATA

Many carers are unknown to the system. Some are supported by a wide range of community organisations and others by carer services.

B

DATA COLLECTED AND REPORTED INTO CENSUS

Limited data collected, data does not feed into census

CARERS IN TOUCH WITH CARER CENTRE

CARER

Contacts Carer Centre

Interacts with social work

CARER CENTRE STAFF

SOCIAL WORK STAFF

Initial conversation

Offer ACSP

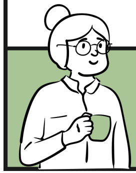
Identify carer

DATA MANAGER

Set up data management system

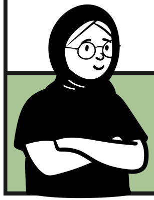
2 IDENTIFICATION OF CARERS: PERSONAS

Responsibility is on carers to find services but if you don't know they exist, there's no way of using or finding them. The best support we get is through social work, we have a budget to access respite every fortnight (although respite services are diabolical and I've had to employ my mother in law to help). I'm planning to attend workshops at the Autism Assessment centre and I managed to get support for my daughter through Charlie House. I've joined a Facebook group about my son's disorder and met 2 other families – having better access to peer groups would be amazing. I've been living with depression for the last 11 years but have only been able to access 1 block of counselling – better mental health services for carers would really make a difference.



B

I previously had a carer support plan but don't think I need one. I keep myself busy going to the gym and for walks and I'm a member of a choir. Every now and then I get away for a night to stay with my daughter. The best support for me is that my wife's care package continues to cover her needs allowing me the freedom to do these things.

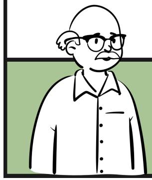


B

I'm very lucky in that my work supports me being a carer and I can leave to help mum when I need to. The carer centre are there when I need them, that support has been excellent and made a lot of difference. With social work you've got to ask for it – I have to say 'I need this help' – I think you don't tend to do this as a carer because it's just one step after another. The Carer Centre had arranged for a getaway for me and then I got all the stress of what happens to mum over this time? Nobody said how to book respite and when I spoke to the centre they said 'oh no, the social worker has to arrange that'. At which point I said, well mum hasn't got a social worker, who's meant to arrange it, how do we do it?

B

I feel lucky to have good family support, although I don't get much of a break as I feel bad asking for one. I don't feel financially recognised for my role, the carers allowance is awful. I feel like a tick box for services and really unsupported, I asked the carers centre for counselling as I struggle with anxiety and depression but was offered jewellery making instead. I would just like somebody to talk to, to get my frustrations out.



B

C

The current dataset limits the number of carers included and the quality of data collected

Carer data is only captured during a formal Carers Assessment (ACSP) and does not capture the complexity of carer needs or the range and impact of support provided.

Key Learning

- As the majority of carers do not complete an ACSP this limits those included in the collection
- As many organisations do not have a role with ACSPs this limits those that are able to respond and submit a data return
- Quantitative data only does not capture the complexity of carer needs
- Only formal support provided under designated headings is recorded

Opportunity

- To engage with carer centres and HSCPs to understand what local information they are able to capture and how it can inform local developments and decision making
- To clarify what information is needed to meet the aims of the census and why
- To work collaboratively with practitioners to develop a dataset that better captures diversity of carer needs and services and the impact of support
- To implement a test of change of the new data set with a small number of local areas

What workshop participants said:

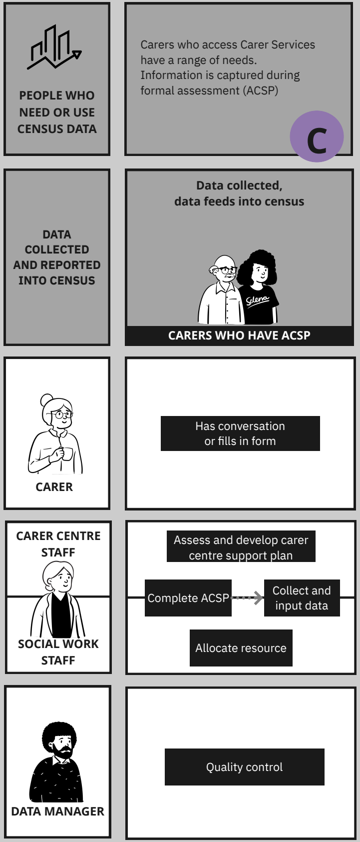
"Data is quite sterile. How do we capture the rich experience of carers?"

"What is asked for in the census doesn't reflect what is happening on the ground."

"Impact of informal support and early intervention? How do we report this? This has grown while formal support has reduced."

"Only 328 carers were offered ACSP – 249 declined."

"The system doesn't really allow for Carers Centres who don't do the ACSP and YCS - very tricky."



PEOPLE WHO NEED OR USE CENSUS DATA

Carers who access Carer Services have a range of needs.
Information is captured during formal assessment (ACSP)

C

DATA COLLECTED AND REPORTED INTO CENSUS

Data collected, data feeds into census

CARERS WHO HAVE ACSP

CARER

Has conversation or fills in form

CARER CENTRE STAFF

SOCIAL WORK STAFF

Assess and develop carer centre support plan

Complete ACSP → Collect and input data

Allocate resource

DATA MANAGER

Quality control

C

The current dataset limits the number of carers included and the quality of data collected

Other observations

- There is significant variance in what is being captured between local areas e.g. some carers centres report all carers, others only if there is an ACSP
- Many carers do not want an ACSP so, although support is often provided, their data is not captured
- The Carers Census does not capture the impact of support provided and if carer needs are being met
- Concerns that the value of preventative support for carers is not being captured
- The Carer Census only captures statistical data which lacks richness
- The Carer Census needs to be capturing the information that is of most value to stakeholders

Opportunities

- To include the capture of information on preventative support
- To recognise other support for carers, that might be more important to them, provided by a wide range of organisations
- To develop clear guidance and quality control measures around a new dataset to reduce variance across local areas

What workshop participants said:

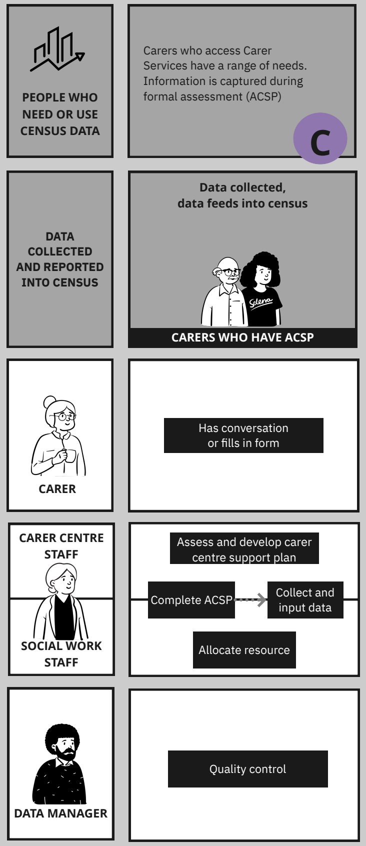
"If a support or intervention has a positive impact for a carer then this is surely more important then the number of something offered/ accepted/declined."

"Important to capture low level support as impacts significantly on the system."

"Making sure all services are collecting same data. Making sure it's accurate and reflects anticipatory/ preventative work – about 70%."

"Gap: measuring and recording outcomes against service delivery to know carers needs are met. Nothing in census right now."

"We reported anyone known to the centre regardless if ACSPs were completed or not."



D

Assessments currently don't always add value for carers

During interviews, carers shared their experience of the assessment process, highlighting some of their challenges and frustrations.

Key Learning

- The importance of having support from staff to complete the ACSP and the challenge when completing this alone
- Assessment can be a positive experience with the carer feeling empowered and acknowledged
- Frustrations when the assessment had been completed but no feedback or further information was received

Opportunity

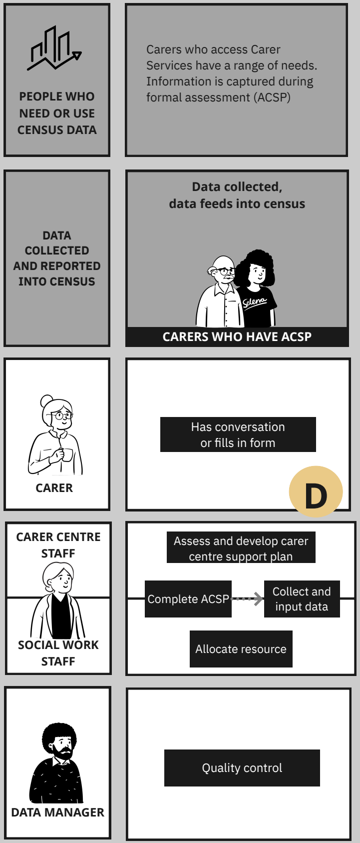
- To engage with carers to understand their experience and what good assessment practice looks like from their perspective
- To develop an approach to monitor carer experience and evaluate impact of any changes in data collection/ assessment practice
- To collaborate with carer organisations to understand existing evidence around carer experience of assessment
- To develop good practice guidance for assessment based on carer experience e.g. including the importance of support to navigate the process
- To monitor impact of assessment, to capture what difference this made, if needs are being met and opportunities for further improvement

What interview participants said:

"I've been through an adult carer support plan but didn't find the process that good. There were a lot of questions and paperwork. I had help from a support worker but all the information ended up on a computer, never to be looked at again."

"I found the assessment form intrusive, it was an ordeal to complete it."

"When I had some time I completed the assessment form, this was over a month ago and I've not heard anything back – the form meant nothing. It doesn't actually feel like an assessment was carried out, just felt like a tick box exercise."



PEOPLE WHO NEED OR USE CENSUS DATA	Carers who access Carer Services have a range of needs. Information is captured during formal assessment (ACSP)
DATA COLLECTED AND REPORTED INTO CENSUS	**Data collected, data feeds into census** **CARERS WHO HAVE ACSP**
CARER	Has conversation or fills in form
CARER CENTRE STAFF **SOCIAL WORK STAFF**	Assess and develop carer centre support plan Complete ACSP → Collect and input data Allocate resource
DATA MANAGER	Quality control

3 ASSESSMENT: PERSONAS

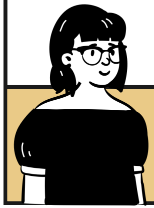
I've had forms to fill in. It's a bit weird, I wasn't quite sure what I should be putting in them. It would have been better to have somebody with me when I filled it in to explain the jargon because for me at the time everything was manic. It was hard filling in the assessment because it made me look at how much I wasn't coping – you're not the one you want to be assessing, you want to be dealing and coping and managing.

D

The whole system has been broken down to box ticking and assessments are really vulnerable to interpretation. Whatever I answered in the first assessment didn't flag up the severity of the issues I had. Knowing how to answer the assessment correctly is crucial to receive the correct support. Now there is a woman at the carers centre that recognises when I'm struggling and helps me with the reassessment which has been a huge help. Just having the assessment is so validating, just the fact somebody listens is huge.

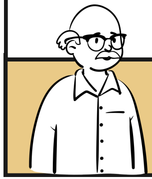
D

I did this thing with the council, a carer support plan. They sent me the form and I just filled it in myself and sent it back. I'm not entirely convinced anybody bothered reading it. Now I find out the social worker has left, I didn't know this and now I feel I have to start again. That's when you feel the exhaustion, the form is sitting there, nothing is happening.



D

The carer link worker helped me complete an ACSP, no way I would have done this on my own. There's a lot of discussion needed in each part and the worker helped me see more clearly what I was doing and identified areas that I needed support with. I was surprised by how much I got upset during assessment. Main thing for me was I felt empowered, acknowledged and listened to – almost validated. It was a really positive experience going through assessment.



D

E There is a risk that data requirements negatively impact on assessment practice

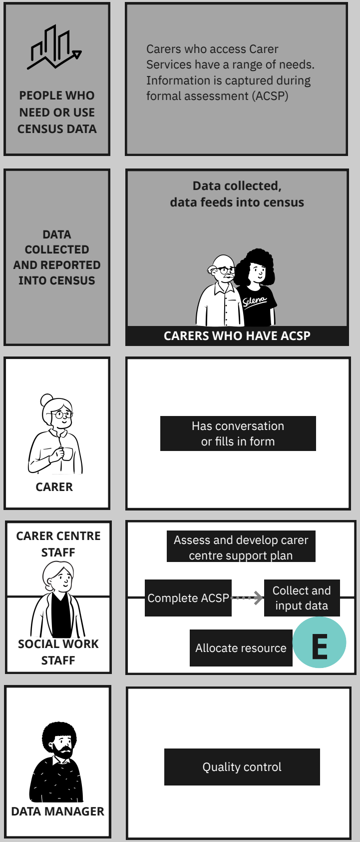
The Adult Carer Support Plan (ACSP) does not routinely add value and detracts from the 'good conversation' approach to carer assessment.

Key Learning

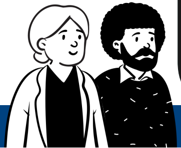
- In many areas a carer centre assessment is often completed and only where statutory services are required will a ACSP be offered and completed
- Language is important: carers might refuse an ‘assessment’ but be happy to have a ‘conversation’
- A carer centre assessment takes a good conversation approach and focuses on personal outcomes planning. Data is not recorded or reported on this activity
- There is stigma for many carers to be referred to social work (where this is the route to access an ACSP)

Opportunity

- To explore current local practice around assessment to identify what is being captured by frontline staff, key learning and good practice
- To consider the language used regarding ‘assessment’
- To involve local stakeholders/frontline staff in developing an approach to data collection that aligns with rather than drives local practice
- To develop an approach to evaluating the impact of data collection on local practice



What workshop participants said:



"There is a concern that collecting data this way is influencing practice, turning a conversation into a tickbox exercise. It's important to consider the carer's experience and journey as well as the need for information gathering."

"Assessment as long or as short as Carer wants to talk then into system - can take a whole day."

"ACSP offered after informal assessment (only if residential respite or home care required)."

"How is information about ACSP communicated? - default answer for carers is no."

"Identifying individual outcomes in a carer friendly way (before adult carer support planning) means some information is not gathered. This process is easy and quick for the carer, but does not necessarily help to fill in the census."

E There is a risk that data requirements negatively impact on assessment practice

Other observations

- Carers centres have difficulty accessing all the data required e.g. cared for person data
- Reluctance to collect all the information as time consuming for the carer and not always appropriate to ask
- Issues with staff capacity due to time consuming assessment process
- Carers often don’t want a separate assessment by social work teams so information not collected
- Carers and families can have concerns about sharing data
- Difficulty in collecting information over the phone – staff welcome the return of home visits to complete the assessment

Opportunities

- To work collaboratively with practitioners to develop a simple assessment/data collection tool

What workshop participants said:

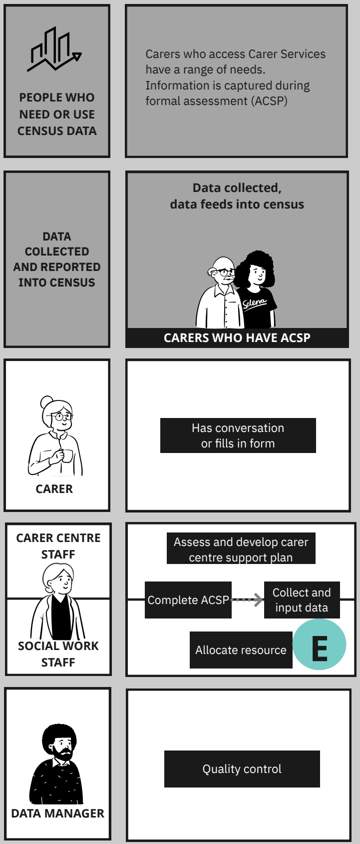
"ACSP is not user friendly – carers are very busy already and the support plan can be onerous with over 100 questions, very personal, not knowing who is controlling that."

"ACSPs have detracted from time the team can spend with carers; felt like assessors not support workers; fear is will become fed up not getting to do what they want to do; want to stop doing ACSP, be outcomes focused."

“Difficult to gather information about the cared for person (GDPR) and connect with the carer especially where there are multiples."

“Not always appropriate to collect data in difficult circumstances.”

"Lack of a sense of how the information is being used resulting in concerns about sharing."



PEOPLE WHO NEED OR USE CENSUS DATA

Carers who access Carer Services have a range of needs. Information is captured during formal assessment (ACSP)

DATA COLLECTED AND REPORTED INTO CENSUS

Data collected, data feeds into census

CARERS WHO HAVE ACSP

CARER

Has conversation or fills in form

CARER CENTRE STAFF

SOCIAL WORK STAFF

Assess and develop carer centre support plan

Complete ACSP → Collect and input data

Allocate resource

E

DATA MANAGER

Quality control

F

Data management systems require significant resource to implement and maintain

Carer centres have developed CRM systems to manage carer data however there are specific challenges regarding the set up and maintenance of these systems.

Key Learning

- Local areas have different systems so lots of variance in how data is being managed and the challenges faced
- Some systems are not set up to capture the data that is required by the Carers Census
- A system for quality control is important but requires resource
- Staff training is required to increase the quality of information put into the system
- Changes to systems take time and it's challenging to keep up to date with data requirements

Opportunity

- To identify and share learning regarding local case management systems
- To create learning opportunities on data management systems for carer centre staff
- To create a 'best practice' case management system that can be accessed by all carer centres
- Provide national support via data specialists to allow carer centres to 'health check' their data quality much earlier in the process

What workshop participants said:

"We usually do data quality checks monthly to identify and address data issues, but during the last 24 months this has been happening less frequently due to other demands."

"Need to enable staff to capture data early on using digital means is less onerous - capacity and resource requirement."

"If Scottish Government want this information then they should be saying here's the database, the training, here's the tools to do this."

"Local carer centre really adapted how info is captured. Info captured from first contact and rich census return being provided."

"It's in how we collect the data, try to make everything in the same format, lack of consistency."

PEOPLE WHO NEED OR USE CENSUS DATA

Carer data is managed by local authorities and carer services using a

DATA COLLECTED AND REPORTED INTO CENSUS

Challenges around data quality mean some is not fed into census

CARERS WHO HAVE ACSP

CARER

CARER CENTRE STAFF

SOCIAL WORK STAFF

DATA MANAGER

Maintain data management system

F

F

Data management systems require significant resource to implement and maintain

Other observations

- Information is added to cared for person data in social work systems.
- Difficulty for staff to separate the carer and cared for person's needs and services when putting information into the system
- Staff need to have the time to put data into the system
- Staff awareness regarding the importance of data: if staff don't understand the value of collecting and inputting then they are less likely to take the time to do it
- Data sharing agreements between carer organisations and HSCPs can work well to enable access to data

Opportunities

- To create clear communication and guidance for staff on the carers census to raise awareness and improve data quality
- To explore opportunity for carer data to be recorded separately within social care systems
- To capture learning and develop guidance on data sharing between local carer organisations and HSCPs

What workshop participants said:

"We have 5 independent centres, data sharing agreements being worked on."

"Barriers still there in system - hoping new system coming in November will pull from different sources to show what's happening for carers."

"More human error in our organisation rather than reluctance or time constraints as cited."

"Everyone is doing this in different ways which can result in incomplete information. There's need for more clarity and training."

PEOPLE WHO NEED OR USE CENSUS DATA

Carer data is managed by local authorities and carer services using a

DATA COLLECTED AND REPORTED INTO CENSUS

Challenges around data quality mean some is not fed into census

CARERS WHO HAVE ACSP

CARER

CARER CENTRE STAFF

SOCIAL WORK STAFF

DATA MANAGER

Maintain data management system

F

6 CENSUS RETURN

G The national Carers Census reporting process does not align with local systems

The process of transferring data from local systems into the Carer Census Excel spreadsheet is incredibly time consuming for HSCP and carer centre staff.

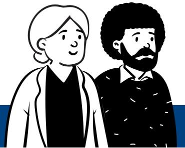
Key Learning

- Carer centres highlight the impact of census reporting on staff capacity, with resources taken away from supporting carers and in some areas the need to recruit additional staff to cope with demand
- Data managers highlight that although the relevant information might be in the HSCP system as it is within the cared for person's record there is not enough time to find it
- Some carer centres are positive as census requirements are built into their CRM system whereas in the majority of areas information is manually being pulled through from every record (depends how information is being input in the first place)

Opportunity

- To complete desktop research and discussion with other Scottish Government departments to learn from existing data collections
- To create a tool that is easier for data providers to input data
- To create space for local areas to learn from each other about what works

What workshop participants said:



"Despite designing our CRM system around the carer census requirements, it is still a very time-consuming task."

"Took 3 months of one person's time to figure out how to transfer from own system to government system. Much of this was manually going through paperwork. Took time away from directly supporting carers."

"Running multiple reports, having to cross check for duplication, if I could run a census report on my system and send it in. If we could just press a button. Do some systems have a better fit?"

"It's manual work to input data into the spreadsheet. The data is received in PDFs. This needs input into the spreadsheet and worked on prior to uploading."

PEOPLE WHO NEED OR USE CENSUS DATA

There are significant gaps in data about unpaid carers in Scotland.

DATA COLLECTED AND REPORTED INTO CENSUS

Challenges around reporting data mean some is not fed into census

CARERS WHO HAVE ACSP

CARER

CARER CENTRE STAFF

SOCIAL WORK STAFF

DATA MANAGER

Report Data G

NHS National Services Scotland
Healthcare Improvement Scotland
ihub

G

The national Carers Census reporting process does not align with local systems

Other observations

- The requirement to complete the Carers Census took staff resources away from being able to provide support for carers
- There is a lack of communication and support for local teams from Scottish Government
- The excel spreadsheet and drop down menus are tricky to use
- Significant lead in time will be required if any changes are being made to the Carers Census

Opportunities

- To engage with data providers to identify what support would be beneficial from Scottish Government
- To create a forum for local areas to access support easily
- To identify outcomes for the Carers Census activity to map progress
- To identify and communicate a clear timeframe if any changes are being made to the Carer Census data set or collection tool

What workshop participants said:

"Scottish Government needs to communicate ask earlier in the reporting process."

"Better and more communication. Advance notice of data requirements, guidance, template, support."

"Sharing of returns - encouraged not to do locally but this could be helpful, carers centre and HSCP can support each other, support deduplication."

"Lack of available support to help with technical issues."

"Can Scottish Government not develop a system to pull through local data that would benefit all areas."

PEOPLE WHO NEED OR USE CENSUS DATA

There are significant gaps in data about unpaid carers in Scotland.

DATA COLLECTED AND REPORTED INTO CENSUS

Challenges around reporting data mean some is not fed into census

CARERS WHO HAVE ACSP

CARER

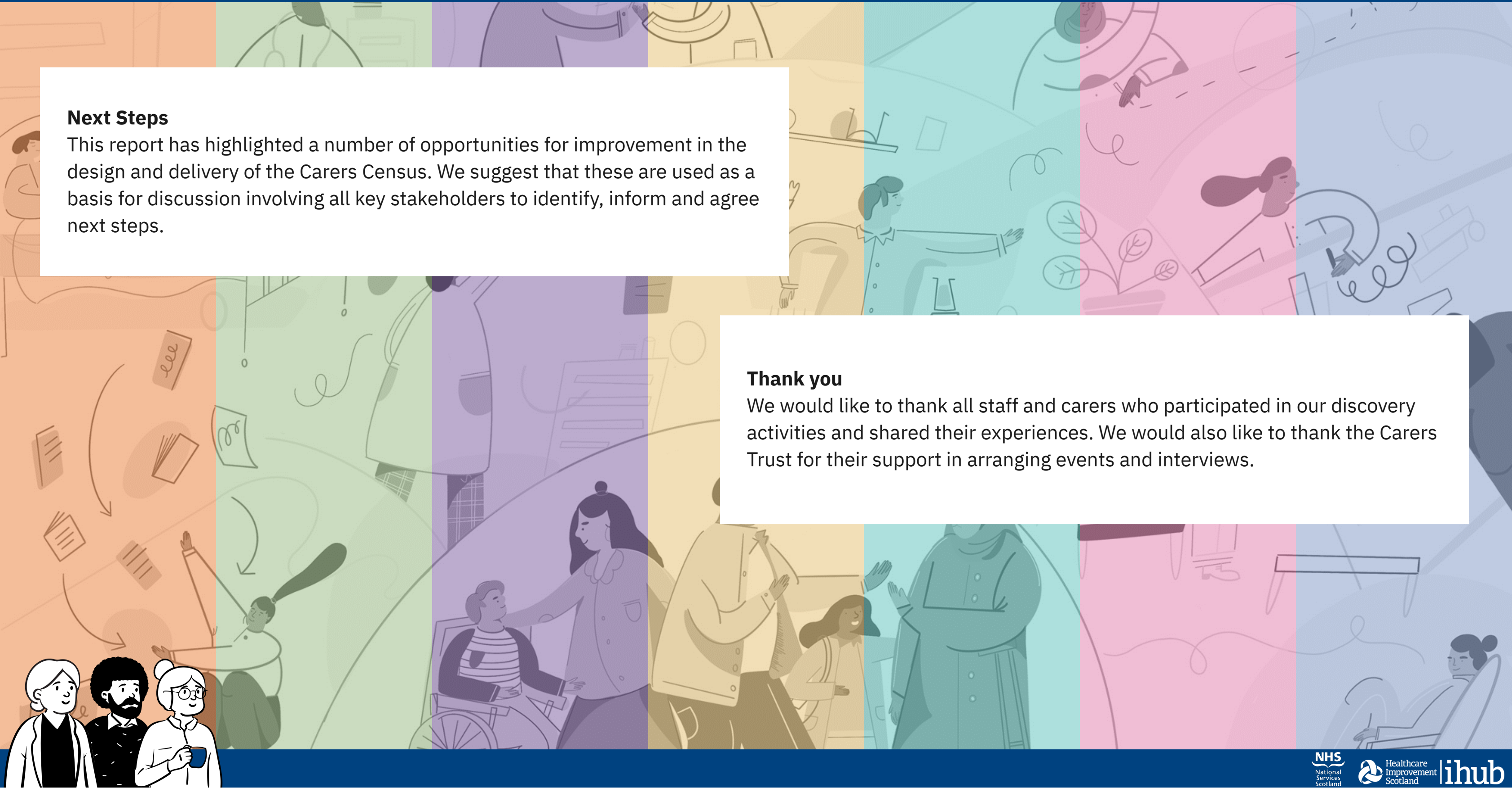
CARER CENTRE STAFF

SOCIAL WORK STAFF

DATA MANAGER

Report Data G

THANK YOU & NEXT STEPS



Next Steps

This report has highlighted a number of opportunities for improvement in the design and delivery of the Carers Census. We suggest that these are used as a basis for discussion involving all key stakeholders to identify, inform and agree next steps.

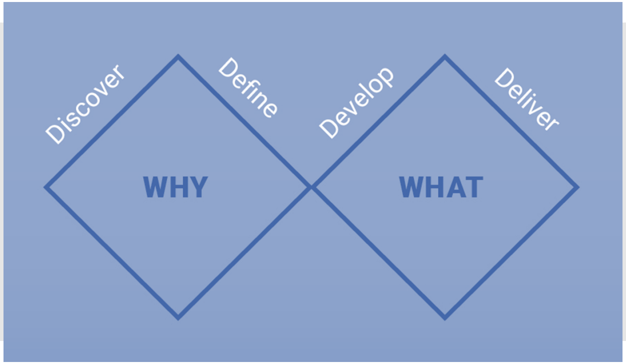
Thank you

We would like to thank all staff and carers who participated in our discovery activities and shared their experiences. We would also like to thank the Carers Trust for their support in arranging events and interviews.

APPENDIX: APPROACH

The Scottish Approach to Service Design was adopted.

The SAtSD ensures that service users are supported and empowered to actively participate in the discovery, definition, development and delivery of services. The SAtSD approach aims to ensure that we don't just design services in the right way, but that we design the right services.



The approach has a set of founding principles:

- We explore and define the problem before we design the solution.
- We design service journeys around people and not around how the public sector is organised.
- We seek users' participation in our projects from day one.
- We use inclusive and accessible research and design methods so users can participate fully and meaningfully.
- We use the core set of tools and methods of the SAtSD.
- We share and reuse user research insights, service patterns, and components, wherever possible.
- We contribute to continually building the SAtSD methods, tools and community.

APPENDIX: METHOD

In this initial discovery phase, workshops (n=6) and interviews (n=20) were conducted with multiple stakeholders from the statutory and voluntary sectors and carers, respectively. Thematic analysis identified cross cutting themes with emerging recommendations on areas for further investigation and next steps.

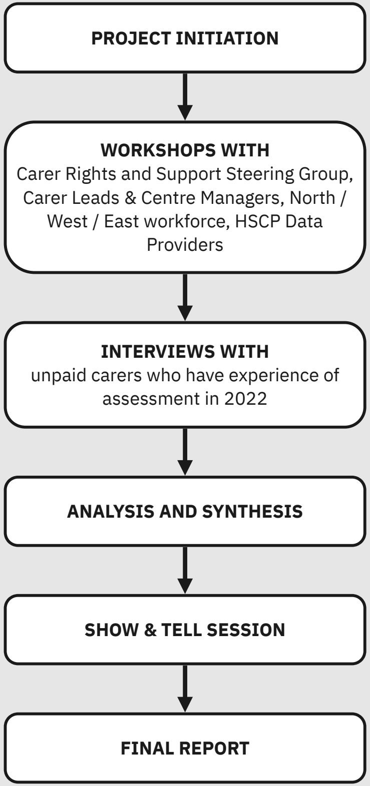
- The research was carried out using a mixture of workshops with Carer Rights and Support Steering Group, Carer Leads & Centre Managers, North, West & East workforce and HSCP Data Providers. In addition, interviews were conducted with carers identified by Carer Centres as having recent experience (in 2022) of assessment.
- Carer journey maps were refined with workshop participants and enhanced with evidential quotes from both workshop and interview participants.
- The workshops and interviews were analysed using thematic analysis. The core themes were then synthesised into problem statements, core needs and opportunity statements with supporting quotes from research participants.
- Collective anonymous feedback on the Show & Tell session is reflected in the final report which elaborates on next steps and recommendations.

Limitations of this project

This project focused on understanding the journey for adult carers. We recognise that significant challenges exist around the collection of data on young carers and there is a need for further exploration with a wider range of stakeholders. However, that is outwith the scope of this research.

Every attempt was made to be inclusive in inviting workshop participation. However, there are gaps in understanding local social work approaches to carer identification and assessment.

Detailed carer interviews captured lived experiences but we cannot be sure these are representative of all carers experiences. We know there is a large carer population who are not in contact with carer organisations as well as carers who do not self-identify as carers.



PROJECT INITIATION

WORKSHOPS WITH
Carer Rights and Support Steering Group, Carer Leads & Centre Managers, North / West / East workforce, HSCP Data Providers

INTERVIEWS WITH
unpaid carers who have experience of assessment in 2022

ANALYSIS AND SYNTHESIS

SHOW & TELL SESSION

FINAL REPORT

APPENDIX: PARTICIPANTS

Workshop 1 was with the Carer Rights and Support Steering Group. It was attended by 12 people representing 5 national organisations and 5 local HSCP / Carer organisations.

Workshop Number	Workshop Audience	Participants	Local Areas	Public Sector	Third Sector
2	Carer Leads & Centre Managers	46	23	28	16
3	North Workforce	19	9	12	7
4	West Workforce	15	5	10	5
5	East Workforce	8	4	2	6
6	HSCP data providers	24	20	20	0

- **Over the course of the research, 113 participants took part in 6 workshops. Eleven people attended more than one workshop.**

- **8 participants represented national organisations, 69 public sector organisations, and 36 third sector organisations. 30 out of 31 HSCP areas were represented.**

- **A total of 20 carer interviews were conducted with participants from East Lothian, Highlands, Lanarkshire, Moray and Western Isles.**

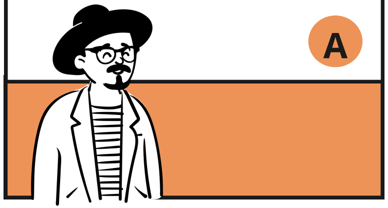
- **This included carers who were looking after their children (n=9), spouse/partner (n=4), parents (n=4), sibling (n=1) or more than one family member (n=2). Several had been in their caring role for over 20 years.**

- **Of the 20 interviewees, 9 had an ACSP completed with social work (n=5) or a Carers Centre (n=4) with the remainder either not reported (n=8) or do not have an ACSP (n=3).**

- **The Show & Tell session presenting preliminary findings was attended by over 30 people of whom 4 returned a feedback form.**

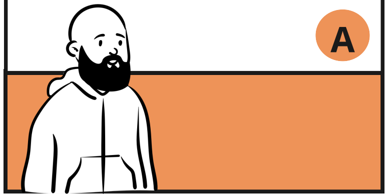
APPENDIX: ADDITIONAL CARER PERSONAS

I've cared for my mum for the last 6 months. Being a carer I feel quite low and upset, seeing my mum deteriorate and not being able to do anything. I quite often have a need for replacement care so I can have a break but there is no staff in agencies here to fulfil these needs. I contacted the carers centre because of how caring was affecting my mental health which had been recognised by my own self and my family.

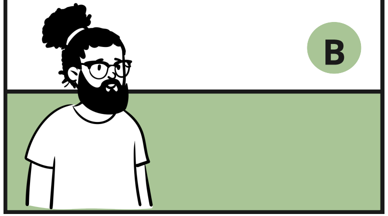


I've been a carer for the past 3 years for my mum. I think it's a privilege but also a responsibility, I often have to chase up the same things again and again and I can be exhausted from lack of sleep. My biggest challenge has been arranging a care package after discharge from hospital using direct payments, I felt really stressed and struggled to get accurate information – the reality is you become an employer on top of being a full time carer. There is plenty of information but not the right information at the right time and no one told me about organisations that can help to set up x, y and z. I still have a lot of anxiety in case a direct payment carer leaves.

I gave up my job to be a full time carer for my daughter who has cerebral palsy. Being a carer means being very busy and having a lot more responsibility than your average parent, I have a constant buzz in my head about what needs to be done. I also worry about what would happen if we both fall ill, one parent always has to be ok. I often feel overwhelmed and underappreciated but it is also fulfilling in a way.

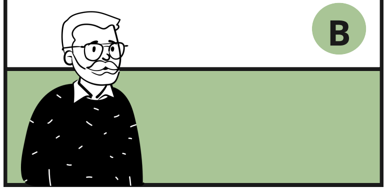


I have two brothers but they don't do a lot to support us - drop the paper in or the occasional shop. I know I can call the carer centre for support – I don't have a laptop so they sorted me out with a grant for a tablet to help with paperwork and they spoke to me about trying to get a wee break. The carers centre send me different literature/ emails but to be honest there might be some things in it but I just don't have the time to look.

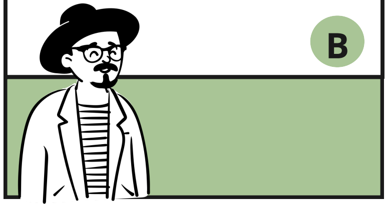


APPENDIX: ADDITIONAL CARER PERSONAS

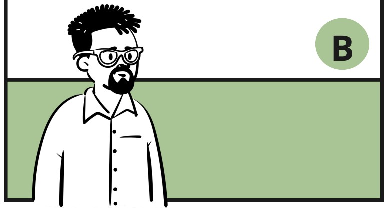
I'm really grateful for the care package. My mum has started a day centre so I have 3 hours to myself to sit in a café and read a book. I also get two and a quarter hours respite per week alongside the care package (although I had to complete an ACSP to access this and I found the form intrusive, all about goals and outcomes). I had to flail about trying to find the local carers centre but they have been helpful in supporting me to access the Government's Short Breaks Scheme.



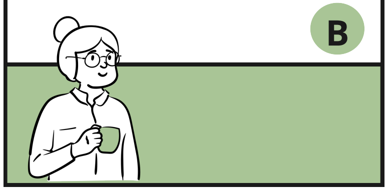
Online courses have been helpful around autism, mindfulness, how to potty train. I asked for help with claiming benefits and Money Matters called to tell me what I should be claiming. The carer centre are really on the ball, emailing me loads of links, holiday funds, family fund, lots of options. They explained about carers allowance – how did I not know all of this – and that I can still work part time under a certain amount. I was completely overwhelmed by finding out so much support is there. If I didn't speak with these people how would I know? I could have saved myself a lot of stress, frustration and anxiety.



I haven't had any assessments and we don't need any support – I'm not finding it onerous or feeling overwhelmed – I'm aware it can be but we are ok for now. My siblings come to stay for a few days so we can go away. I know there is a local carers' coffee catch up but I choose not to go.



The counselling service offered has been the greatest benefit and has improved my mental wellbeing. I also get support from talking with other carers at online activity sessions – they are connections rather than friends but it's invaluable support. I don't get respite as yet but maybe I will in the future.

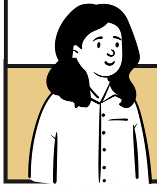


APPENDIX: ADDITIONAL CARER PERSONAS

I've been through an adult carer support plan but didn't find the process that good. There were a lot of questions and paperwork. I had help from a support worker but all the information ended up on a computer, never to be looked at again

D

I had a carer assessment arranged but I was running late and I've not heard back from them since. I haven't bothered to arrange another one, I don't see the point in it as the support they can provide I can do myself.



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When I had some time I completed the assessment form, this was over a month ago and I've not heard anything back – the form meant nothing. As a carer I feel I need to argue and fight everyone, don't want to chase up the assessment after rejection. It doesn't actually feel like an assessment was carried out, just felt like a tick box exercise

D

I found the assessment form intrusive, it was an ordeal to complete it. At assessment I think there should be a dialogue of options and assessors need to be clear about the reality and implications of accepting the options of Direct Payment or social work care package.

D