

**Carers Act: Data collection and monitoring
Third meeting of short-life working group**

Wednesday 24th August 2016

Room GN.07, St. Andrew's House, Edinburgh

Attending: Mike Brown - Social Work Scotland (chair)
Philip Brown - City of Edinburgh Council
Lynn Gallacher - Borders Carers Centre
Donna Hamilton - Falkirk Council
Fraser Mitchell - Fife Council
Fiona McCulloch - Greater Glasgow and Clyde
Heather Noller - Carers Trust
Ben Hall - Shared Care Scotland
Julie Rintoul - Health and Social Care Analysis, SG
Alexandra Rosenberg - Health and Social Care Analysis, SG
John McLean - ScotXed, SG
Martin Devine - Health and Social Care Analysis, SG

Apologies: Susan Webster - East Dunbartonshire Council
Fred Beckett - Glasgow City Council
Julie Young - The Dixon Community
Don Williamson - Shared Care Scotland
Lynn Lavery - Carers Policy, SG
Stewart McIntosh - ScotXed, SG

Mike went through the minutes and actions from the second meeting. Several changes and additions were suggested:

- Add action item to request Glasgow colleagues (a) to provide the fields used to collect carers' information in CareFirst; (b) to provide more information whether and how voluntary sector assessment or advice and support services access CareFirst.
- On page 3, add "and a paper Mike had circulated on the record selection criteria" to the first sentence of the minute under Data specification.
- Correct the penultimate paragraph on page 3 to read: "Therefore, the data spec should use both existing and new terminology for the baseline year".
- Carry forward live actions to the agenda for the next meeting.

These have been included in a revised version of the minutes.

Lynn was not able to attend the meeting, so her action (to check the exact position on local/national eligibility criteria, and report back to the group) was not completed.

This led to a discussion of eligibility criteria, and if these would be set locally or nationally - there is tension between the desire to devolve authority to the lowest reasonable level and trying to avoid a 'postcode lottery' where the level of service varies between areas. The feeling is that these are likely to be local - if so, eligibility criteria should be included in the data collection, to provide context for the carer data.

Outcomes paper

In Lynn's absence, Julie presented the paper on outcomes.

The SG is wary about collecting data on outcomes such as “feel supported to continue caring” at national level through this survey as outcomes such as these are already collected consistently and anonymously through the Health and Care Experience Survey (HACE). If the data is used for benchmarking, this could potentially affect the way that services are provided. In order to carry out robust analysis of outcomes data at national level, the data collected/provided by local authorities would need to be standardised (at least to some extent), meaning that there would be less flexibility for local areas to collect data to suit local circumstances.

One of the [National Health and Wellbeing Outcomes](#) refers specifically to carers (Outcome 6. People who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health and well-being.), so there is already some focus on outcomes for carers. Some areas, however, will have issues in collecting and providing outcomes data - for example, where their IT systems need to be updated to include outcomes, or where significant effort is required to process and utilise outcomes data.

The paper suggested that the current approach of using survey data supplemented by academic research to provide information on outcomes should continue. In particular, the Health and Care Experience Survey (HACE) is a useful source of data on outcomes for carers:

- a large sample size (over 100,000 responses overall, with around 15,000 of these being carers)
- is consistent across the whole of Scotland allowing comparisons to be made between local areas.
- the sample covers the whole population of Scotland, so will potentially pick up people providing unpaid care who are not known to local authorities or other organisations providing support
- HACE collects data directly from carers, not through an intermediary (e.g. a social worker), so may be a more direct measure of outcomes.
- independent of local authorities

- need to be aware of potential bias caused by this being a self-selecting survey (i.e. the data is made up of those who choose to respond to the survey)

Relying on surveys for data on outcomes, and so not including outcomes in this data collection, could lead to a disconnect between inputs to support for carers and the outcomes of carers supported. It cannot be assumed that spending (more) money on support for carers will lead directly to improved outcomes for carers - need to look at all of the data available in combination.

In addition, not asking for outcomes data may mean that outcomes are seen as less important, leading to a slower pace of change.

There are many potential drivers of improvements to carer's outcomes and the support services provided meeting the needs of carers - for example, voluntary organisations, health and social care partnerships (meaning that the NHS is involved). While local authorities provide an important part of the support available to carers, they do not necessarily deliver support directly.

One of the potential uses of the data to be collected is to analyse the financial impact of the Carers Act. Multiple sources of data, including outcomes data from the HCES, were used in preparing the Financial Memorandum for the Act. It was difficult, however, to translate this data into something useful for predicting/projecting costs or numbers of people - in particular, it is difficult to correlate/combine the data collected from the various surveys and other data sources. For example, there is no way to combine the Scottish Health Survey data on support received by carers with the outcomes data from the HCES.

Action: SG to look at what can be done to improve the interaction between data sources (for example, to improve the consistency of questions used in surveys, to make the results more directly comparable)

Data specification

The rest of the meeting was used to go through the data specification, alongside a short note produced by Mike (see Annex) setting out the high level data outputs required from the Carers Act Monitoring.

When thinking about the data that should be collected, we need to consider how this data will be used and the outputs that will be of most importance/interest. This will provide information on the relative importance of the data items to be collected.

Title page: Including 2017 on the front page could imply that this is a one-off data collection rather than an ongoing collection over multiple years. It was agreed that it would be better to remove the year.

Terminology used (throughout document): The data spec currently uses the new terminology (ACSP, YCS, etc.), but it is likely that some areas/people will continue to use existing terms (e.g. assessment) until the Act comes into force. It was agreed that both old and new terms are used (e.g. referring to assessment/ACSP) for now, with the data spec to be updated to use only new terminology once the Act comes into force.

p2: 'Deadline for form' not really appropriate for this type of data collection - use 'Deadline for submission' (or something along these lines) instead?

p4: Broken link in table of contents - need to update.

p5: Extend the list in the first sentence of the first paragraph - '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.'

This is an example of a wider point brought up during the meeting - the current data specification concentrates on what local authorities can provide. Other organisations provide significant amounts of support to carers, so will often be better sources of data than LAs. The data collection specification should be updated to reflect this, and it may be very useful to run a separate/bespoke consultation with other carer organisations.

Action: Ben to provide information on known Carers Centres and other organisations that provide support to carers, and any known gaps.

Action: SG to consider the form of consultation with the NHS, third sector and other carer organisations.

Typo at end of first paragraph - 'cacers' should be 'carers'.

p6: Wrong e-mail for the ScotXed unit - should be ScotXed@gov.scot

p7 (Record selection criteria): The aim here is to capture all carers known to local authorities and other relevant organisations.

How well can local authorities provide/collect data on these criteria? It is likely that other organisations will know of/provide support to more carers than local authorities

- this suggests that building links between the various organisations involved will be important to ensure that as many carers as possible are picked up in the data collection, but it may be difficult to build these links.

The criteria includes people who have declined assessment - it is likely to be difficult to get any more than minimal information on these people.

The last bullet point on the inclusion criteria list is intended to be a 'catch-all' (to pick up carers who do not come under any of the other criteria), but was thought to be too wide-ranging - it would be very difficult for local authorities and other organisations to capture these people in the data collection.

Do the data collection criteria, as currently specified, cover all support provided to carers? In particular, there will be people who do not meet the eligibility criteria for support, but receive support from other sources - will these people be picked up in the data?

Assessments can be offered to carers by many different people and organisations - it is likely to be difficult to get data on assessments from some sources (e.g. GPs, district nurses) because the data is not recorded, or because data is not transferred between the systems of the organisations involved. This suggests that there will be a gap in the coverage of the data collection - in particular, where different organisations use different or incompatible systems. (This could indicate a future line of development for the systems used to collect/store data on carers.)

If (data/admin) system improvements are required, how will these be funded? The consultation should include something on systems and the infrastructure required to collect/provide the data - current systems, data currently collected, improvements needed, etc.

While collecting appropriate and accurate data is important, we need to be aware of the bigger picture - the main aim is to achieve the best outcomes for carers. When setting up the data collection, we need to take care not to put any hurdles or obstacles in the way of providing the services required (e.g. by making the data collection overly complex, or collecting data that is of little use) - need to find the right balance.

On data submission: The ScotXed data input system is very flexible, with multiple methods of submitting data (so users can choose the most suitable method for them/their data) and the facility to have more than one person entering data for an area - for example, it is possible for a local authority's data submission to include input from the local authority, carer's organisations and NHS facilities within the area, with the dataset including information on which user provided each part of the data

(potentially useful for identifying the source of the assessment/who identified the carer).

Frequency of data collection: This is still to be decided, even though the data spec implies that this will be an annual collection in some places. SG's current thinking is that this will be an annual collection once it is established, but that starting with a quarterly collection would be useful - this will allow quicker identification and correction of problems and issues. The data specification is expected to evolve over time, and receiving feedback on how it works in practice more quickly will help to improve the spec in time for implementation of the Act.

Action: Include frequency of data collection in the covering letter for the consultation.

p8 - potential overlap with Social Care Survey: The SG want to avoid collecting the same data more than once, particularly where this could result in two different data collections giving inconsistent results for the same thing. There is some overlap between the data already collected in the Social Care Survey and this proposed new data collection.

There are potential issues around Self-Directed Support and linking to the carers data - need to make sure that these two datasets are linkable.

p9 - list of variables included in collection: Mike pointed out that the data collection did not include anything on respite/short breaks and replacement care. While there are known issues with collecting this data (particularly around completeness of data after the introduction of SDS), current respite provision involves a significant cost - estimated at around £200m based on the last published data. Local authorities will want to be able to monitor the demand for respite/short breaks and replacement care.

There is some confusion over the difference between short breaks and replacement care. Replacement care is a component of a short break or respite - the care provision that is required to allow the carer to have a short break. A short break is the break for the carer from their normal caring duties - the aim of a short break is for both the carer and cared-for person to benefit.

Most of the cost of respite will be for replacement care, but there will be other components - for example, the creative and innovative ways of providing a break for a carer that have started to be used over recent years.

It was proposed that replacement care should be added to the list of bullets on p9, under 'For the person that they care for', but we need to specify the data on replacement care that should be collected.

Action: For all - think about replacement care data (both what should be collected and what is available), and feed back at the next meeting.

At this point, it was obvious that we weren't going to get through the data spec in the time available, so there was a brief discussion on arranging another meeting of the group. While it would be possible to do the remaining work without another meeting (i.e. through e-mails and telephone conversations), this would be more difficult and less productive than another face-to-face meeting - as a result, it was agreed that another meeting should be arranged, and that it ideally should be longer than 2 hours.

Action: Julie/Martin to make arrangements for another meeting of the SLWG, and to contact members of the group to check on availability.

p10 - data definitions: These should be extended to include:

- any 'technical terms' in the inclusion criteria
- the current carer's assessment
- the types of support

CHI/unique identifier: The CHI is a unique reference number used for health care purposes

p15 - Gender: An 'Other' option could be included, but numbers in this category are likely to be very small - in practice, 'Other' would be combined with 'Not Known' for analysis purposes.

p17- Care hours: The number of hours of care provided are not necessarily a good measure of the impact of providing care on the carer (e.g. the impact on a person who provides care in addition to working full time is likely to be greater than on a carer who does not work). While it is still worth collecting data on care hours, it would be useful to collect data on the impact that providing care makes to the carer's quality of life.

p17 - Length of time spent caring: This should be added to the carer data to be collected.

p17 - Care type: The data spec currently contains only three options - others should be added:

- transport

- support/supervision
- emotional support
- an 'Other' option (with free text field for more detail?)

p17 - Care level: At least some LAs may not be collecting this data, so this field may not be well completed initially.

Amount/level of care that the carer is able to provide - this is likely to be different to the amount/level of care that the carer is willing to provide, so should be included in the data collection.

p18-22 - Cared-for person data: There are potential Data Protection issues around the cared-for person data:

- linking the carer data with the cared-for person data (to identify carers who are also cared-for persons)
- the potential for collecting data about a person without their knowledge or consent

The aim of a potential linkage of the carer and cared-for person is to get more information about the relationships between carers/cared-for people - potentially useful for identifying certain types of carer (e.g. parent carers). It would be possible to do this without data linkage by adding a question on the carer's relationship to the cared-for person. In the same way, adding a question on if the carer is receiving care/support would allow identification of carers who are also cared-for people - can extend this to include the amount of care received and the source of care.

Any changes to this should be considered in the context of the inclusion criteria - may need to adjust the inclusion criteria to minimise/eliminate gaps in the data to be collected.

The identifiable data in the cared-for person section (name, date of birth) is not needed for analysis, but could potentially be useful for data linkage if the CHI number has not been provided. (Post-meeting addition - MD: These fields have been encrypted in other health/social care data collections to allow the data to be used for linking, but removing the identifiable/personal nature of the data.)

p23 - CAJoint: The ACSP and YCS are individual assessments - remove the references to ACSP/YCS from the description? It was also questioned whether reference to joint assessment should be included in the survey as it could encourage bad practice.

Other points relating to the data spec:

- Should there be more 'Not Known' options?

- Support needs - while there is a question asking what type of support is required, it would be useful to collect data on the amount of support required.
- Support provided - this needs to be defined more tightly in terms of volume of support provided.
- Collecting data on costs - the cost of additional demand resulting from the new Act needs to be monitored and further thought is required about how this can be done. Asking for data on costs is likely to lead to inconsistent data, so it was felt that asking for volume/hours data and converting this to cost using an average cost per hour will be more reliable.

Action: Any comments/questions/issues with the spec should be sent to Julie Rintoul (julie.rintoul@gov.scot), Martin Devine (martin.devine@gov.scot) and Mike Brown (mikevbrown@blueyonder.co.uk).

Next meeting

The initial plan for the SLWG was to have three meetings, but there is enough work outstanding to justify having one more meeting - date/time/location to be confirmed.

Annex: short note tabled at the meeting by Mike Brown (Social Work Scotland)

**Carers Act Monitoring – data collection outputs (excluding outcomes
workstream)**

To assess the impact of the Carers Act (compared with 2017-18 baseline) over time (in each reporting period from 1.4.18) on:

- (1) Numbers of carer assessments: requested, offered, completed)
- (2) Number of carers assessed as eligible for support
- (3) Number of carers receiving support, by type of support
- (4) Of which, number of carers receiving a short break
- (5) Number of carers with completed short breaks, by number and duration of breaks, type of break, and (ideally) the cost
- (6) Number of carers whose cared for person received replacement care (respite).
And/or: number of people cared for with completed replacement care episode.
By: number and duration of episode, type of respite, and (ideally) the cost.

Notes:

- These data outputs require further specification, for both case selection and tabulation.
- Further work required on SDS issues (and cross-over with Social Care Survey), including taking into account loss of information when the carer opts for a Direct Payment under SDS Option 1.
- Further work required on financial data collection.