

SHORT-LIFE WORKING GROUP - BASELINE DATA SPECIFICATION FOR CARERS (SCOTLAND) ACT 2016 - DISCUSSION PAPER - PERSONAL OUTCOMES

Introduction

1. At the last meeting of the SLWG, there was a discussion on whether or not it was desirable to capture personal outcomes as part of the data specification for the collection of baselines data, to inform implementation of the Carers (Scotland) Act 2016 (Carers Act). SG were asked to consider and put forward a paper to the group.
2. This paper therefore explores the options for collecting data about personal outcomes, considers the level at which data could be collected and considers the arguments for and against collecting such data as part of the baseline data specification. It also makes a proposal for the way forward.

Personal Outcomes – data collection options

3. There are three levels at which it is possible to collect data about personal outcomes, in support of Carers Act implementation:
 - **Macro level** – i.e. collecting data about personal outcomes in order to establish whether the Act is being successful in meeting its stated objectives; this would not be based on collecting individual data about whether a carer's personal outcomes had been met or partly met, but would be based on surveys or academic research, some of which is likely to be longitudinal;
 - **National level** – i.e. collecting data about the extent to which a carer's personal outcomes had been met or partly met, based on either individual data collected locally and then collated, or based on wider surveys (such as the [Health and Care Experience Survey](#) or a combination of both);
 - **Local level** – i.e. collecting data about the extent to which a carer's personal outcomes had been met or partly met, based on individual data collected locally.

Advantages and Disadvantages of each approach

Macro level

4. There is a clear case for collecting data about the achievement of personal outcomes, at macro level, as a key piece of data in helping us understand the extent to which the Act is being successful in achieving its stated objectives. However this is outside the scope of the short life working group and will be taken forward as part of a separate workstream to consider what measures will be necessary to monitor and evaluate the progress of and success of the Act.

National level

5. While it is possible to collect information about personal outcomes at national level (and therefore forming part of the data specification the SLWG is producing) we need to be clear about the case for doing so. Given that the monitoring and evaluation workstream will consider what qualitative and quantitative research and other measures are required, and that there are no plans to discontinue the current collection of data via the Health and Experience Survey, there would only appear to be a case to collect individual data at national level.
6. Collecting individual personal outcomes data at a national level is only worthwhile if it is consistent and comparable across the country. This raises a number of issues:
 - If local authorities use different personal outcomes frameworks to fit local circumstances, there are likely to be inconsistencies in the data provided between local authorities
 - If a national standard for data collection is implemented in order for outcomes data to be consistent and comparable across the country, local authorities will have less flexibility in designing local outcomes frameworks
 - It is likely that at least some local authorities would need to make significant changes to their data recording systems in order to collect the data required
 - There is a risk that the outcomes data will be used for benchmarking between local authorities, shifting the emphasis away from providing the most effective support to carers, towards meeting statistical targets
7. Other potential issues involved with collecting data at a national level are:
 - Personal outcomes may change within the measurement period, to take account of reviews or changes in circumstances and we would need to consider how to reflect this;
 - We would need to consider whether to collect data separately for adults and children;
 - There is an assumption that collecting this data would involve [a practitioner] in making a judgement about whether the carer's personal outcomes have been met, in full or in part, which may not necessarily reflect the view of the carer.
8. Given these complexities, it is not clear what collecting such data at national level would achieve, over and above existing data collected from the Health and Care Experience Survey¹. This data can be collected within consistent parameters and because the questions are likely to stay the same from survey to survey (although additional questions may be added) it is possible to see a trend over time.

¹ See Annex1

Local level

9. At **local level**, there is a stronger case to collect data about whether individual carers' personal outcomes are being met, as this information could be used to assess the effectiveness of the organisation and personal outcomes processes, the quality of the support provided and to feed into potential service improvements. However this can be driven by local needs and since it is to inform local developments it is not necessary to specify this nationally.

Proposed Way forward

10. At a macro level, the monitoring and evaluation workstream will take forward wider work to establish what data is necessary to establish whether the Act is successful in achieving its stated objectives. **It is proposed that any output from the SLWG discussion around personal outcomes can be fed into this work.**
11. Although it is possible to collect individual personal outcomes data at national level, it is not clear what this would achieve and there are inherent difficulties in putting in place a system to collect the data consistently and draw national conclusions from it. However, there is an intention to continue to collect data about the achievement of personal outcomes via the Health and Care Experience Survey. **It is proposed therefore that we do not attempt to collect this data at national level.**
12. One further option might be to consider a proxy measure as part of the baseline data specification which can be specified and which would provide some consistency in results. It is intended for example to collect information about whether support is provided to the carer and the type of support provided to the carer as a result of the adult carer support plan or young carer statement. Since the support provided must (under the provisions of the Carers Act) contribute towards the achievement of the carers' personal outcomes, it could be assumed that the provision of support of itself meets the carer's personal outcomes. Such a measure would not provide an indication of the extent to which this was considered to be the case, however this could be supplemented with data from the Health and Care Experience Survey from which some measure of comparison could be inferred. **The group are asked to consider whether this is an acceptable compromise.**
13. At local level, local authorities would be free to collect their own data about the achievement of personal outcomes in order to drive business and service improvement. **It is not however proposed that this is included as part of the national data specification for baseline data to support the Carers Act.**

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Health and Care Experience Survey - Q45 - outcomes for carers

The Health and Care Experience survey includes a question to collect data on outcomes for carers. The question in the 2015/16 survey is:

How much do you agree or disagree with the following about how you feel as a carer most of the time?

- I have a good balance between caring and other things in my life
- Caring has had a negative impact on my health and wellbeing
- I have a say in services provided for the person(s) I look after
- Local services are well coordinated for the person(s) I look after
- I feel supported to continue caring

(Responses are on a 5-point scale - Strongly agree, Agree, Neither agree or disagree, Disagree, Strongly disagree.)