Response to the consultation on

Adult Social Care Data Developments 2012

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This document is a response to the 'Adult Social Care Data Developments 2012' consultation on behalf of the National End of Life Care Intelligence Network (NEoLCIN) (www.endoflifecare-intelligence.org.uk). The South West Public Health Observatory is the lead public health observatory for end of life care.

We have consulted with colleagues in the National End of Life Care Programme to collate the following response. Our response includes feedback from Mr Rick O'Brien (End of Life Care Lead, ADASS.)

We have also completed Section 1 of the consultation, 'Respondent information and general questions' separately.

Background and why we are responding to this consultation

The NEoLCIN was established by the National End of Life Care Programme (NEOLCP) in 2010 to support the intelligence requirements of the National End of Life Care Strategy (2008). It has produced numerous reports, guides to data sources, indicator sets and analyses on end of life care.

We will shortly publish Local Authority End of Life Care Profiles (8th August 2012), which will present over 50 end of life related indicators for each local authority in England. These will be publicly available on the NEoLCIN website.

The profiles include 16 social care indicators. Unfortunately, there are no indicators in social care that measure care provided specifically and only at the end of life. We have therefore presented data for populations aged 65+. Inevitably, therefore, there are limitations in what we can conclude from this data. However, we chose to include the social care indicators to:

- Provide context for those working in end of life care, particularly in terms of giving an overview of the social care landscape, and

- Highlight the limitations of current social care data for end of life care and support efforts to improve it.

Overall, the profiles aim to:

- Help identify and understand variation in end of life care across England so that effective policies can be developed locally and nationally

- Support the commissioning and planning of end of life care services locally and nationally

- Highlight information gaps and inadequacies so that data collection on end of life care can be improved, and

- Meet the information and intelligence requirements set out in the National End of Life Care Strategy (2008), particularly that end of life care information should "encompass both health and social care and wider societal issues related to end of life care".

Some sample profiles and a metadata guide are attached to show how we have used the social care data.

Our priority

To be able to identify people approaching the end of life in social care data, in order to improve the support we give to policy, commissioning and service planning for end of life care.

Our response

The stated aspiration of this consultation – to focus future social care data returns in ways that align with key policy changes, such as personalisation and prevention, and focus on outcomes – are very welcome, especially where such principles are supportive of improving public health and, in particular, the quality of end of life.

We do, however, have some concerns.

It is difficult to see how information in the consultation will enable local authorities to embed the delivery of the Supporting People to Live and Die Well framework into revised social care data/outcomes collections. Yet this will be key to ensuring it is part of Council with Adult Social Services Responsibilities (CASSR) core business delivery in adult social care. In view of demographic trends and economic realities it is vital that these issues are addressed, monitored and evaluated.

Items to Drop, New Replacement Collections on Finance, Short and Long-term Support (SALT) [activity data], and Safeguarding collections proposed for 2013/14

ASC-CAR and RAP returns include several data items for areas we know to be of great importance to those nearing the end of life, including reports on transfers and activity. It is not clear how the newly proposed ASCOF/ SALT collections may provide an alternative which is of better quality, or whether (even if desirable) they are achievable in practice.

We are concerned that the ability to accurately monitor and evaluate these areas could be impeded, especially during transition. We would argue strongly for measures such as an overlap period in collections, and specific reports, to compare and contrast old and new data collections both during and after transition. This would help users of the data to cross reference old and new collections better and should ideally add the benefit of demonstrating the value of the new collections.

A similar argument, advocating overlap and specific transition correlation reports, would apply to the transition from AVA collections to the new Safeguarding returns. Regrettably, this remains an area which can affect quality of life at the end of life, as well as at other times of vulnerability, and it is important to have good quality data in order to advocate on behalf of those who can no longer present their own view.

We would also argue strongly for development of an effective indicator of joint planning between health and social care, especially as there is an historical problem with intermediate services and 'step up and down beds'.

Regarding finance indicators, there is insufficient information in current indicators to see the actual levels of net contributions made solely from dedicated Council funds throughout all the unit costs categories. So it is difficult to be clear about the proportion of gross expenditure met solely by the local authority and the proportions met by other categories of provision. For example, NHS Section 256 contributions can be calculated by deducting 'Gross expenditure on Residential and Nursing Care less NHS Section 256 contributions' from the larger 'Gross expenditure on Nursing and residential care' total, but the remainder may exclude other contributions from NHS that fall outside of Section 256.

Similarly, figures for expenditure on these and other unit cost categories (Home Care, Day Care/Day Services, Meals) include contributions from some (but not necessarily all) individuals who pay for part or all of their own care in a local authority area, and contributions from other sources such as charities. It will be important to add clarity to these data streams so that joint working can be facilitated.

The New Framework for Equalities and Classifications

It is clear that a lot of work has gone into developing a system that is intended to help promote better equality. We welcome the use of common classifications throughout all of the new social care collections, as this will improve consistency. However, we still have concerns that the very nature of the data collection and presentation system will continue to put serious limitations on the types of analysis that can be done if it is not possible to analyse at a multi-factorial level (between items in this classification and other items),for example, ethnicity and health condition. It is often this level of analysis which enables us to identify areas where intervention can most effectively lead to improvements.

The lack of a key classification for people known to be receiving end of life care in social care data is a significant barrier to the analysis that can be conducted by the NEoLCIN. It has resulted in the restriction of our indicators to people aged 65 years and over. Yet we know that younger people require end of life care and social care. We wonder whether the inclusion of such a key, perhaps based on the three triggers approach would be feasible. (See Appendix summarising the three triggers approach.)

The proposal to replace Primary Client Group with two new classifications (Primary Support Reason and Health Condition/Cognitive Disability) is also broadly welcomed. However, the same problem arises, as for other equalities proposals above, regarding multi-factorial analysis. Also the Primary Support Reason and Health Condition/Cognitive Disability classifications may present challenges to data integrity and quality where a person experiences rapid changes. It is also important that those completing these fields understand the importance of, and technical issues involved in, recognising and recording chronic health conditions which may have contributed to a more obvious acute crisis. Joint working between health and social care to clarify any links between these new classifications and those in health data (where appropriate) would be welcomed. Please could you advise us regarding any plans for this?

Regarding changes proposed to age bands, our initial analysis indicates that there may be peaks of social care demand in two generalised groups: those areas where higher than average percentages of residents live in the most deprived quintile; and those where higher than average percentages of residents are aged 85 and over. However, in more deprived areas fewer people than average die at age 65 and over (more die younger). We need to be able to identify relevant data for people known to be nearing end of life and receiving social care in all available age bands.

National Minimum Data Set for Social Care (NMDSSC) Workforce Data

In order to promote improved joint working between health and social care we anticipate that Clinical Commissioning Groups will probably find local social care workforce data useful alongside similar data for local healthcare workforces. In brief:

Q1   all data items are important

Q2   all data items are important

Q3   LA data collection: 'reason for leaving' – we suggest this is included

Q4   Individual level data: qualifications, year started in main job – we suggest these are included

We need to know how much social care resource is aimed at end of life care, specifically at service and client level. Thinking about organisation level data there would be value in being able to identify:

- the number of people receiving a service for end of life care, and the hours allotted

- the number of workers and whole time equivalences apportioned to end of life care

- the number of vacancies in end of life care roles (with demographic and economic changes, this will be important to monitor and evaluate), and

- the reasons for leaving end of life care posts.

Surveys

We believe that the current Adult Social Care Survey is likely to under-represent or exclude the views of people who are receiving end of life care, particularly because guidance states that:

- "Selected service users who are incapable of responding even when special steps are taken to accommodate their frailty, illness or disability should be treated in returns to the NHS Information Centre as refusals rather than ineligibles.

- If anyone selected for inclusion in the sample dies before the survey is carried out they should be excluded from the data return

- If the service user does not have the capacity to consent to take part, then they should be removed from the sample and replaced.

- Alternative methods of data collection should not be the norm for all service users and should only be used where requested by the service user "

Consideration should be given to survey of relatives or carers of deceased individuals, and those too frail to participate despite special steps taken to accommodate their frailty, illness or disability. A national VOICES survey does this for health care.

In addition, we are in favour of much greater independence from Local Authorities in the collection of data for the survey.

Adult Social Care Outcomes Framework (ASCOF)

Domain 1 (Enhancing quality of life for people with care and support needs) and Domain 2 (Delaying and reducing the need for care and support) proposed new measures

The consultation focus is on:

1. effectiveness of long-term services in supporting people to achieve personal outcomes, and

2. changes in the measures for the proportion of people who receive self-directed support, and those receiving direct payments.

Changes to highlight and monitor the contribution of social care (long-term and short-term), specifically to quality of life at end of life, are needed but seem to be missing. At the very least, it would be helpful to separate data for people identified as approaching the end of life within the changes proposed. However, even this might leave a gap in information about the contribution made through short-term services.

Also, it is not clear whether the new data streams proposed will allow monitoring of the numbers of people referred and/or completely assessed who die prior to receipt of packages of care, or who were refused them.

We believe that the following key measures and outcomes should be in local ASCOF accounts, and some of these should cross reference to best practice in the delivery of local accounts:

- numbers of people with social care support plans in place expressing their views about end of life care support (e.g. through a shared end of life register)

- numbers of social care providers with contracts including end of life care standards and outcomes

- outcomes of service users and carers consulted about their end of life care support needs

- numbers of people assisted through social care support to die in their home (including, domiciliary care, care homes and supported living)

- reported outcomes based on dignity in care, and wellbeing for those receiving end of life care support.

- skills of workforce outcomes for staff supporting service users with end of life care needs

- social care support for people with long-term conditions (e.g. dementia, chronic obstructive pulmonary disease (COPD)) where end of life care support needs have been agreed with carers

- measures/outcomes supporting integration in end of life care support – lead professional model, shared pathways on discharge from hospital, shared health social care support plans, and

- experiences/outcomes of carers supporting service users with end of life care needs.

Appendix

'Three Triggers' is cited by Yorkshire and Humber Public Health Observatory report on End of Life Quality at:

http://www.yhpho.org.uk/resource/view.aspx?RID=144435

The original source is the Palliative Care and the GMS Contract Quality Outcomes Framework Guidance Paper (2006). The three triggers listed are:

1. The surprise question – 'Would you be surprised if this patient were to die in the next 6-12 months?'

2. The patient makes the choice for comfort rather than curative care

3. Specific indicators of advanced disease for the 3 main groups described above (cancer, organ failure and elderly frail/dementia) indicate that the patient is approaching end of life.)