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Ed Humpherson | Director General for Regulation

Rt Hon Jeremy Hunt MP Chair, Health and Social Care Committee House of Commons London SW1A 0AA

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Dear Mr Hunt,

I write in response to the Health and Social Care Committee's call for evidence for the inquiry considering *Social Care: Funding and Workforce.*

The Office for Statistics Regulation¹ (OSR) is the independent regulatory arm of the UK Statistics Authority². We provide independent regulation of all official statistics produced in the UK, including those in Devolved Nations and the NHS³. Our regulatory work is underpinned by the Statistics and Registration Service Act 2007.

We set the standards official statistics must meet through the statutory Code of Practice for Statistics⁴. We ensure that producers of official statistics uphold these standards by conducting assessments against the Code. Those which meet the standards are given National Statistics status, indicating that they meet the highest standards of trustworthiness, quality, and value. We also report publicly on system-wide issues and on the way statistics are being used, celebrating when the standards are upheld and challenging publicly when they are not.

In January 2020, the OSR published findings from an in-depth review of Adult Social Care statistics in England⁵. We are using this report as the basis for our submission to the Committee, the findings of which have never been more relevant as society adjusts to the rapid changes resulting from the ongoing coronavirus (COVID-19) pandemic.

There are gaps in the data and information that might tell us about the real cost of providing social care and ensuring good outcomes for people who need social care. Our review finds that this important sector of public policy is very poorly served by data. Social care has not been measured or managed as visibly as hospital care. The gaps in data and analysis make it harder for individuals and organisations to make informed decisions.

We want to see improvements to the existing statistics, as well as more fundamental changes. This will require a cross-government commitment to improvements. We strongly encourage the implementation of joined up data across health and social care to understand how the two systems interact, and what drives the best outcomes.

¹ https://www.statisticsauthority.gov.uk/osr/

² https://www.statisticsauthority.gov.uk/about-the-authority/

³ https://www.statisticsauthority.gov.uk/about-the-authority/uk-statistical-system/producers-of-official-statistics/

⁴ https://www.statisticsauthority.gov.uk/code-of-practice/

⁵ https://www.statisticsauthority.gov.uk/publication/report-on-adult-social-care-statistics-in-england/

Our review highlighted three main areas for attention:

- Better leadership and collaboration across the many different organisations involved in the process of publishing official statistics on social care, that enables working across boundaries to join-up government departments, local authorities and between public and private sector providers.
- Addressing gaps in available data as most information available comes from local authorities with responsibilities for adult social services and does not cover private household expenditure, privately funded care, or the value of unpaid care, meaning the total cost of social care provision remains unknown.
- Improving existing official statistics through accessibility, coherence, quality, timeliness, and granularity of the data to provide insight and allow existing data to better meet user needs.

We have said for some time that there is no parity of measure between the health and social care sectors. The COVID-19 pandemic has had a significant impact on care homes and clearly shown that the approach to measurement in the social care sector has been lacking. In a response to the disease, there is now more data available on social care – this should continue after the pandemic ends.

The Committee may also be interested in our other work in response to COVID-19. This includes rapid regulatory reviews of new outputs from the Government Statistical Service, and statements advocating improvements to the presentation and availability of data on COVID-19⁶.

We will continue to work with a range of organisations to make the case for improvements to social care statistics in England and more widely across the UK. We hope to raise the profile of these issues through this submission.

I look forward to seeing the conclusions of your inquiry. Please do not hesitate to contact me if I can be of any further assistance.

Your sincerely,

Ed Humpherson

Director General for Regulation

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⁶ https://www.statisticsauthority.gov.uk/osr/what-we-do/assessment/covid-19-changes-to-statistics/

Overview

- 1. This submission is based on the findings from our review of Adult Social Care Statistics in England published in January 2020.
- Adult social care is a large and important area which requires strong evidence to support
 effective policy development, delivery of care and personal choice. Better data
 infrastructure and outputs which address the gaps in existing data are essential for
 individuals and organisations to make informed decisions
- 3. Improved data matters in solving problems, supporting efficiency, and maximising outcomes. It is also important to inform decisions made by individuals about the care they receive or provide for themselves and their families. Collaboration across traditional boundaries, across public and private sectors, is necessary to deliver the coherent and complete picture of adult social care.

Better leadership and collaboration

- 4. There needs to be a strong voice to champion statistics that meet a range of user needs and strong leadership to implement the required changes. Many different organisations are involved in publishing official statistics on social care. Making improvements will require collaboration across government departments; local authorities; and between public and private sector providers.
- 5. In line with the introduction of new technologies⁷ to assist healthcare, we want to see progress made with proposed infrastructure that will support the integration of health and social care data so that there is a better understanding of the interaction between health and care and an individual's experience. We welcome plans set out in the government's vision for digital, data and technology⁸ in health and care. We hope the establishment of NHSX, a body to 'progress digital transformation of the NHS', will allow government to deliver on this ambition while considering data needs. There is also potential for the Office for National Statistics (ONS) to support the sector through innovative approaches to data analysis, such as data linking, and use of provisions in the Digital Economy Act.

Addressing data gaps

- 6. There are significant gaps in what adult social care data currently measures:
 - Delivery of social care outside statutory control: Statistics on social care activity are
 primarily sourced from data provided by Councils with Adult Social Services
 Responsibilities (CASSRs). The established assessment criteria mean that many
 individuals privately funding care or receiving informal care have little or no contact with
 a local authority. CASSRs can therefore only measure part of the picture. These limited
 data have to act as a proxy for the whole social care sector. The information on unmet
 need and future demand is also limited.
 - Funding outside statutory control: There are gaps in understanding of the scale of household expenditure on privately funded care and the value of unpaid care. There is no official estimate of the value of unpaid care provided by family and friends, but unofficial estimates that do exist vary between £100bn⁹ and £132bn¹⁰ per year, far

⁷ https://www.gov.uk/government/publications/the-future-of-healthcare-our-vision-for-digital-data-and-technology-in-health-and-care/the-future-of-healthcare-our-vision-for-digital-data-and-technology-in-health-and-care

⁸ https://www.gov.uk/government/publications/the-future-of-healthcare-our-vision-for-digital-data-and-technology-in-health-and-care/the-future-of-healthcare-our-vision-for-digital-data-and-technology-in-health-and-care

⁹ https://www.nao.org.uk/wp-content/uploads/2018/07/Adult-social-care-at-a-glance.pdf

¹⁰ http://www.carersuk.org/images/News__campaigns/CUK_State_of_Caring_2019_Report.pdf

- exceeding HM Treasury spending¹¹, giving a sense of the unacknowledged value of this support.
- Individual experiences and quality of care: There is little information on pathways and transitions between health care and social care – new infrastructure is required to effectively address this. There is also little information on the quality of care and outcomes for those who experience social care.
- 7. The gaps identified are significant and need to be addressed in order to support effective delivery and facilitate improved outcomes for those who experience social care. There is public and policy interest in knowing about social care activity and spend wherever it happens, whether in the home, in a residential home or nursing home. The traditional route of relying on data collected by local authorities to complete official statistics is not enough.

Improving existing official statistics

- 8. Looking across existing statistics on adult social care we found some good examples of insightful analyses, However, there were many instances where we identified that improvements were necessary. There are improvements which should be made to the existing official statistics, around:
 - Accessibility
 - Coherence
 - Quality
 - Timeliness
 - Granularity of the data
- 9. Changes in these areas could improve insight and allow the existing data to better meet user needs. We welcome the ONS proposals for a portal to signpost users to existing social care statistics, and want to see all producers of social care statistics take on the recommendations we have set out in letters to the relevant Head of Profession for Statistics following our detailed review of official statistics outputs as part of this review.
- 10. We will continue to work with a range of organisations to make the case for improvements to social care statistics. We hope to raise the profile of the issues highlighted in this report and work towards parity of esteem between health and social care statistics.
- 11. Improved statistics can support policy makers who are developing proposals to reform delivery of adult social care, as well as individuals who will be able to hold government to account and make better informed decisions about the issues impacting their lives and their families.

Data and statistics on COVID-19 impacts on the care sector

- 12. Statistics on COVID-19 in the care sector including care home outbreaks, the number of suspected COVID-19 cases in care homes, and registered deaths in care homes involving COVID-19 are currently released through a variety of different reports including daily and weekly surveillance reports and within weekly registered death releases. These statistics start to provide a picture of the impacts on those receiving care and help decision makers to understand and manage COVID-19 within care settings. However, further analyses are needed to provide context and facilitate a better understanding of key areas for concern.
- 13. To further improve these statistics, we suggest producers continue collaborating to present a coherent picture of the impact of COVID-19 on those in care settings across the UK. For

¹¹ Latest figures from HM Treasury show that public expenditure on personal social services in England (table 10.1 of that report) amounted to £24.5 billion in 2017/18, and this does not include the significant private expenditure on social care - https://www.gov.uk/government/statistics/public-expenditure-statistical-analyses-2019

example, the ONS is collaborating with the Care Quality Commission in England and the Care Inspectorate Wales to publish early estimates of COVID-19 related deaths in care homes¹². We welcome these new data and efforts and recognise that producers are seeking to develop statistics provision in this area.

- 14. Producers also need to explain the wider context of COVID-19 and the large number of deaths for those in care settings. There is a need for information to contextualise the data and statistics on deaths in the sector as well as to support management of COVID-19.
- 15. Alongside this, producers need to understand and assess the impact of any changes in the circumstances and context of data sources, and any implications for use should be clearly explained. Within the varied landscape of statistics and data on those in care settings, producers should make the definitions within their outputs clear to users. For example, clearly identifying statistics as deaths involving COVID-19, deaths due to COVID-19, or deaths of those with a positive test result.
- 16. Producers should work closely with relevant parties, such as the Care Quality Commission, to understand and investigate any changes in the recording of COVID-19 on death certificates which may impact on the accuracy of the data on deaths in the care sector.
- 17. There is a need for producers to provide or enable regional comparisons where possible, with guidance and contextual information to support the interpretation of the statistics, as well as UK comparisons where possible. Guidance should be provided on whether the data from different countries of the UK can be compared to help users understand and interpret the statistics. The similarities and differences between the country-level data should be clearly explained, particularly any differences in care provision, differences in the characteristics of the population of those receiving care, and data collection methods that could affect the ability to make comparisons.
- 18. The OSR has also published a full statement on data and statistics around the impact of COVID-19 on the care sector¹³.

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¹²https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/numberofdeathsincarehomesnotifiedtothecarequalitycommissionengland

¹³ https://www.statisticsauthority.gov.uk/news/data-and-statistics-on-covid-19-impacts-on-the-care-sector/