**Increasing the Coherence of English Health and Care Statistics**

1. **Introduction**

As producers of health and care statistics, we have been challenged by the Permanent Secretary at the Department of Health and the National Statistician to “raise our game” in providing informed advice to policy makers through increased insight and analysis of the data we hold. We are committed to working together to develop improved insight and analysis, drawing on expertise and data from across our organisations, to inform the analytical service we offer to Health Ministers and other decision-makers such as heads of NHS England and PHE.

Additionally, feedback from recent consultations and stakeholder events has highlighted a number of areas where greater collaboration would be helpful for ours users including health professionals, researchers, analysts and the public.

An ‘information service’ which offers user-relevant insight and analysis adds value to the very rich and plentiful data produced by the system.

As producer bodies we welcome the UK Statistics Authority’s active engagement with the users and producers of English health and care statistics. This has highlighted some key priorities for us as producers to address and has been a constructive enabler for us in building increased collaboration.

The Statistic Authority’s Health and Care Summit, held in July 2016, identified some key strategic messages[[1]](#footnote-1). This plan describes how, collaboratively as producer organisations, we are seeking to address these challenges.

Specifically, this plan considers:

1. The development of a single place from which users can access the full range of English health and care statistics;
2. Creating an information service for users, focussed on particular topics as appropriate;
3. The role of senior leaders of the health and care system and how we engage with them to provide strategic leadership, unlock resource and make decisions beyond the remit of the producer groups;
4. The development of a principle-based approach to the statistical responsibilities of the different organisations that currently produce numerical information;
5. Engagement with the Administrative Data Research Network to establish a communication plan to engage further with the public on the issue of access to microdata and data sharing; and
6. Working effectively with international partners who produce health and care statistics to learn from their experiences and to share our own best practice.

This plan has been developed collaboratively across our organisations.

1. **Governance**

Many of the priorities outlined above will be addressed through a new governance structure we have introduced. This governance is described here and referenced in the activities that follow.

All groups have representation from across health and care bodies, including ONS, NHS Digital, DH, NHS England and Public Health England. Other organisations and users are included as appropriate.

***2.1. English Health Statistics Steering Group (chaired by ONS)***

* Develop and own a strategy for English Health and Care Statistics
* Improve coherence and accessibility of health and care statistics
* Oversee topic networks, provide advice on priorities, tackle barriers to delivery
* Lead the implementation of recommendations from the health round table and subsequent summit.

***2.2. Health and Care Publications Advisory Board (chaired by NHS Digital)***

* Advise on the prioritisation of statistical publications
* Take a user-centric approach to the presentation of statistics that cut across organisational boundaries

***2.3. Health and Care topic networks (e.g. cancer, smoking)***

These groups report to the English Health Statistics Steering Group. They will lead development on specific topics as determined by EHSSG in consultation with users. The groups will:

* coordinate user engagement and deliver a seamless service to users
* identify priority areas for development with the topic
* coordinate publications, analysis and advice (reporting to PAB)
* reduce duplication and deliver efficiencies

A workshop of members of EHSSG and policy colleagues is being arranged for early 2017 to discuss and agree themes and the priority topics for which networks should be established. Each topic group will be responsible for developing their own work plans, agreeing and reporting on these to EHSSG.

Networks have already been established for smoking, cancer and mortality. Work plans for these topics will be agreed by **31st March 2017.**

Where significant work is required, this will need to be factored into departmental work plans and the pace at which improvements can be delivered will be dependent on the resources available and agreed priorities within our organisations. Support from senior leaders may be required if we are to secure the resources needed to deliver the objectives of the networks. We will work collaboratively to agree roles and responsibilities across our organisations, taking into account our respective policy responsibilities and available resources.

The EHSSG will review the success of the first topic networks by **30th September 2017** and agree the next tranche of topics for which to establish networks.

***2.4. UK Health and Care Statistics 4-Countries group (chaired by Scottish Government)***

* Consider UK Health and Care Statistics: focussing on providing comparability within the UK
* Share best practice and developments
* Identify areas for greater collaboration

1. **Action plan**

Plans at the moment are focussed on delivering increased coherence in health and care statistics in England. The 4-countries group described in 2.4 will be kept informed of progress and initiatives will be adopted across the UK as and when appropriate.

Underpinning all the development work is an agreed classification of themes and topics. This will inform the topic networks and proposals for how we improve the accessibility of health and care statistics. Themes and topics will be discussed at the workshop mentioned in 2.3 and agreed by **31st March 2017**

***3.1 A single point of access for health and care statistics***

We are investigating the creation of a single point of access (potentially a web portal) for English health and care statistics. Current activities are:

* Reviewing existing mechanisms for accessing data, analysis and advice. This includes the work currently being undertaken by NHS Digital to make improvements to their publication system and the ongoing development of a GSS-wide publication system.
* Identifying the data and analysis to be signposted via the access mechanism

This work is being directed by the EHSSG (see 2.1 above) and taken forward by ONS.

Proposals for delivering a single point of access, including costs, benefits and the sustainability of any solution will be agreed by **31st March 2017**.

***3.2 Creating an information service for users, focussed on particular topics as appropriate***

An ‘information service’ which offers user-relevant insight and analysis adds value to the very rich and plentiful data produced by the system.

A key function of the topic networks (see 2.3 above) is to determine how to provide such an information service on their topic. By establishing a network and sharing information on the work each organisation does on a theme, we should be able to provide a seamless service to users, drawing and building on the data and expertise held across our organisations.

Examples of where our collaborative working has already resulted in an improved service to users are provided in Annexes A and B.

***3.3 Strategic Leadership***

The English Health Statistics Steering Group will develop and own a strategy for English health and care statistics. EHSSG will seek the agreement of this strategy and related plans with the senior leadership and appropriate governance in each of the producer bodies. The Group will provide guidance to the work of the topic networks in accordance with the strategy.

It will be challenging to secure the resource to deliver the activities set out in this plan, given our existing roles and responsibilities. We are working together to reduce duplication and improve data sharing which should free up some resource for those activities. However, on occasion, we may need to seek senior support to help determine relative priorities and to secure additional resource if required.

Where issues of direction or obstacles arise that are beyond the scope of the EHSSG, the Group will raise these with the appropriate senior leaders for advice or resolution. This may include agreeing the roles and responsibilities of our respective bodies, particularly any recommendations to move work between organisations.

An agreed strategy for English health and care statistics will be published by **30th June 2017**

***3.4 A principle-based approach to the statistical responsibilities of organisations***

The EHSSG will agree principles for how we work best across organisations. These will take account of policy responsibilities, where data are held, expertise and the resource available to deliver the work plans.

The topic networks will consider the organisational responsibilities for their topic in accordance with these principles and the agreed strategy for English health and care statistics.

Where the topic group consider there is a case for the transfer of work between organisations, they will escalate this through the governance described above.

These principles will be drafted by EHSSG and presented to senior managers within our organisations for approval by **31st March 2017**

***3.5 Engagement with the Admin Data Research Network***

We are engaging with the ADRN and other relevant initiatives to investigate the potential for providing greater insight through linking data across a range of sources, including census, survey and administrative data.

A workshop of key stakeholders will be held in early 2017, in partnership with the Administrative Data Census Programme, to identify key requirements, data sources and opportunities.

A report setting out options and recommendations, taking account of existing legal gateways and developments in data sharing legislation, will be produced by **31st May 2017**

***3.6 Working effectively with international partners to learn from their experiences and to share our own best practice***

We will continue to be actively involved with international initiatives to improve health and care statistics and make better use of international comparative data to inform policy and healthcare quality. Our analysts regularly make best use of international evidence to inform their work. We consider part of our role to be helping users to be aware of the international information that is available and the topic networks described in 2.3 will consider the practical mechanisms they can offer to achieve this.

We seek to contribute as leaders in good practice and to learn from sharing the experience of others. For example there is good collaboration on the OECD Healthcare Quality Indicators and cancer survival comparisons.

We play a leading role in international bodies when relevant, and represent UK public health policy interests. For example NHS Digital hosted the 2015 WHO classifications conference and ONS are providing expert input into ICD-11 development.

A key contact point on data collections and mainly technical matters is the UK International Health Data Coordinating Group which is convened by NHS Digital, and includes all relevant departments including the devolved administrations.

We will promote the exchange of knowledge and professional development of analysts through involvement in international associations and activities, such as the European Association of Public Health. Learning through exchange visits and conference participation will be encouraged, subject to budgetary restrictions.

We will promote the benefits of knowledge exchange and capacity building with lower income countries, in association with DFID, WHO and other organisations as appropriate. For example the need to make major improvements in civil registration and vital statistics has been recognised by the UN and WHO for the African Region in particular. In 2016, ONS provided 'train the trainer' familiarisation with the IRIS cause of death software for a doctor from Tanzania, sponsored by the US Centers for Disease Control.

1. **Table of actions**

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| **Action number** | **Action** | **Owner** | **Deadline** |
| 1. | Work plans for smoking, cancer and mortality topic networks agreed by EHSSG | Producer lead (see Annex A) | 31st March 2017 |
| 2. | Review of topic networks | EHSSG | 30th Sept 2017 |
| 3. | Agree next tranche of topic networks | EHSSG | 30th Sept 2017 |
| 4. | Proposed final list of themes and topics for EHSSG approval | ONS | 31st March 2017 |
| 5. | Proposals for single point of access to health and care statistics | ONS | 31st March 2017 |
| 6. | Strategy for English health and care statistics agreed | EHSSG | 30th June 2017 |
| 7. | Principles for working across organisations, including roles and responsibilities agreed | EHSSG | 31st March 2017 |
| 8. | Recommendations for delivering greater insight through linking data | ONS | 31st May 2017 |

EHSSG is will oversee the delivery of these actions and approve outcomes

**Annex A: A case study: Cancer Survival and Incidence Statistics**

**Background**

Cancer Survival and Incidence Statistics form a corner stone of the [health statistics landscape](https://www.statisticsauthority.gov.uk/wp-content/uploads/2016/03/Annex-B-Health-Statistics-Landscape.pdf). Historically ONS aggregated cancer registrations from across 9 registries in England to create England level statistics.

In 2013 the remit for collating cancer registrations fell to the newly created Public Health England (PHE). PHE developed a new Cancer Registration System to record cancer incidence and allow the efficient production of cancer statistics.

**Recent developments**

Over the last 18 months ONS and PHE have working together to remove any duplication of effort in the processing of Cancer Registrations. Analytical collaboration is helping to deliver new innovative outputs to meet the priority policy needs of the Department of Health, NHS England and the All Party Parliamentary Group on Cancer.

This has lead to a number of successful joint initiatives:

1. Rationalising systems – ONS, PHE and NHS Digital are collaborating to move to PHE’s new Encore system. This ensures that there is only one source of cancer registration statistics and delivers efficiencies in processing.
2. Joint publication – ONS and PHE analysts collaborated to publish the first national bulletin on [Cancer Survival by Stage of Diagnosis](https://www.ons.gov.uk/releases/cancersurvivalbystageatdiagnosisexperimentalstatistics2012to2014). This analysis helps policy makers to understand the impact that early diagnosis has on cancer survival for different types of cancer and demonstrated clearly the benefits of plans to improve early diagnosis. A new ONS/PHE intra-departmental survival team is now working to deliver new cancer survival statistics.
3. Quality assurance of statistics – ONS and PHE experts collaborating to quality assurance National Statistics bulletins on cancer incidence prior to publication, sharing expertise to provide context to explain trends.

**Benefits**

These initiatives have improved the timeliness of data as well as the narrative and explanation around the statics, resulting in an overall improvement in the service provided to policy makers on Cancer.

The collaboration has also had wider benefits:

* it has helped build subject matter expertise across organisations
* identified the potential to deliver significant cost savings across government
* released resource to work with other organisations to deliver impact in the cancer community, for example we are now collaborating to develop new 10 year survival measures for the Government’s [Cancer Dashboard](https://www.cancerdata.nhs.uk/dashboard#?tab=Overview), which is used to monitor the performance of Clinical Commissioning Groups.

**Annex B: Further examples of collaboration**

A few (but by no means all) further examples of collaboration are provided here.

Enacting consultation: NHS Digital’s recent consultation has highlighted a number of areas where greater collaboration would be helpful for users, which we will work to deliver as part of our response – including disseminating some of our statistics through tools such as Fingertips and working with the RNIB to reach a more targeted audience for our registered blind stats.

Smoking statistics: Statisticians from ONS, NHS Digital, PHE and DH met in September to discuss how their respective outputs on smoking statistics could be presented in a more joined-up way.  The focus on this initial meeting was to understand what each other produced including the timing of reports and any methodological differences.  All agreed to aim towards an approach where future reports are released at the same time and that methodological differences are removed where possible, and explained where not.  This should meet the overriding aim of giving a more coherent set of statistics on smoking to the end user whilst still being able to meet DH requirements to monitor and develop government policy.  The group intend to meet again before the end of the year to focus on some of the detail involved in achieving this aim.

Learning disabilities: NHS Digital has now collected [data](http://digital.nhs.uk/media/10807/GPES-Customer-Requirement-Summary-for-Learning-Disabilities-Observatory/pdf/GPES_Cust_Req_Summary__LDO.pdf) for the Learning Disabilities Observatory at PHE and will be releasing a joint/collaborative publication later this year where they will provide some commentary and direction and we will pull together the headline messages. We will be producing a fairly short, user-friendly report (one page summaries of key messages with charts, infographics, etc) along with a csv file and technical guidance.

Drug related deaths: ONS has been working across agencies to help understand the rise in drug-related deaths in recent years, in particular with Public Health England. Bringing together evidence from across the statistical system has enabled a better understanding of the increase in deaths, for example heroin deaths have increased and we have used data from the National Crime Agency showing rising purity as a key factor. Closer relationships have meant ONS is working closely with PHE to develop new insights to understand this area further involving a deep dive into coroner’s inquests. Without this relationship understanding what new evidence is required would be difficult.

Understanding rise in deaths in 2015: Since building close relations between ONS and the PHE mortality surveillance team there have been several areas of collaboration. One being the concern about a spike in deaths around winter 2014/15.

Waiting for the routine statistical bulletin would mean a lengthy delay to investigate this but working in partnership ONS and PHE produced a joint piece of analysis. Working together meant ONS could focus on specific cause of death analysis and PHE could use their health intelligence to understand the emerging trends. This provided important evidence to inform 2016/17 plans for national and local level winter flu planning, potentially saving lives in the future.

1. https://www.statisticsauthority.gov.uk/wp-content/uploads/2016/08/final-note-of-the-Health-and-Care-Summit.docx [↑](#footnote-ref-1)