

## RSS final response to the Cabinet Office consultation<sup>1</sup> on better use of data in government

### 1. Introduction

- 1.1. Data are the lifeblood of today's economy and society. The UK, like many other countries, has been undergoing radical change in the way data are used to inform better decisions. Although the data revolution has touched almost every sector and industry, this has not happened equally across sectors. Despite support within government for our information economy and better use of data to inform decisions, some areas are hampered by the lack of progress in sharing the data government already holds.
- 1.2. This is very much evident in the production of official statistics. The UK's statistical system is running behind other countries in utilising existing data to inform the public and policy makers on the state of the economy and society. This lack of efficient data access has been most clearly established in relation to the future of the decennial Census, which many countries have replaced with cheaper systems that are based on administrative data. Although the Office for National Statistics is making some progress towards this goal, it is clear there are stumbling blocks which prevent this vision from happening.
- 1.3. The most recent case for better data sharing for statistical purposes was made in the *Independent Review of Economic Statistics*,<sup>2</sup> which was commissioned by the Chancellor of the Exchequer and the Minister for the Cabinet Office in 2015. One of the Review's recommendations is to *"Remove obstacles to the greater use of public sector administrative data for statistical purposes, including through changes to the associated legal framework, while ensuring appropriate ethical safeguards are in place and privacy is protected."*  
*[Recommended Action 10]*
- 1.4. The Royal Statistical Society (RSS) welcomes the government's acceptance of all of the Independent Review's recommendations, including this one. We are therefore fully supportive of the Cabinet Office proposal to give the UK Statistics Authority greater powers to access data for statistical purposes, whilst ensuring privacy safeguards are in place. Nevertheless we have some concerns around the details of the proposed approach, which are set out in Section 3 below.

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<sup>1</sup> <https://www.gov.uk/government/consultations/better-use-of-data-in-government>

<sup>2</sup> Professor Sir Charles Bean (2016) *Independent Review of UK Economic Statistics* (PDF). Available from: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/507081/2904936\\_Bean\\_Review\\_Web\\_Accessible.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/507081/2904936_Bean_Review_Web_Accessible.pdf)

1.5. In addition, we have a strong interest in improving data sharing for research purposes. This is represented in our *Data Manifesto*, which identified 10 areas for improvement in government policy and practice in relation to the use of data and evidence.<sup>3</sup> As set out in our manifesto notes, research evidence is a key component in the development, implementation and evaluation of government policy.<sup>4</sup> It is clear that the research community needs appropriate means of accessing data that is held by government, and we are fully supportive of the principles underlying the current Cabinet Office proposals for access to de-identified data for research purposes. Again, however, we have some concerns on the detail of these proposals. Comments in Section 3 consider support mechanisms for the legislation: infrastructure, skills, potential for bottlenecks in data access requests, and defining public good appropriately with regard to the research process.

1.6. Earlier in April we released an initial Statement (included in Appendix 2) that set out areas of interest in the consultation, primarily supporting that the UK Statistics Authority does need greater powers to access data for statistical purposes, to a level similar to what is in place for the OBR (Office for Budget Responsibility).<sup>5</sup> To frame our further comments in Sections 2 and 3, we would also like to re-iterate from our Statement two of our concerns about what is missing from the consultation document:

1.6.1. Health and social care data are of essential interest to research and statistical communities. It will be hugely important to ensure that the Cabinet Office's proposed provisions for research making use of government data in general are implemented in a way that harmonises with research access to patient data from the NHS, so that health information and other relevant information can be linked in pursuit of legitimate research questions. Recent public dialogues and polling supported by the Wellcome Trust have made valuable presentation of the nuances in public views on this.<sup>6</sup> The lack of clear provisions for health data access is a missing piece for the research community.

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<sup>3</sup> RSS (2014) *Data Manifesto* (webpage), available at: [www.rss.org.uk/manifesto](http://www.rss.org.uk/manifesto)

<sup>4</sup> RSS (2016) *Putting evidence at the heart of policy debate* (PDF), available from: <http://www.rss.org.uk/Images/PDF/influencing-change/2016/data-manifesto1-putting-evidence-at-the-heart-of-the-policy-debate.pdf>

<sup>5</sup> RSS (2016) *Statement on the Cabinet office consultation 'better use of data in government'* (PDF), 1 April 2016, available from: <http://www.rss.org.uk/Images/PDF/influencing-change/2016/RSS-Statement-on-Better-Use-of-Data-consultation-April-2016.pdf>

<sup>6</sup> Ipsos MORI SRI (2016) *The One-Way Mirror: Public attitudes to commercial access to health data: report prepared for the Wellcome Trust* (PDF), available from: <https://www.ipsos-mori.com/researchpublications/publications/1803/Commercial-access-to-health-data.aspx>

- 1.6.2. Non-public bodies, such as private companies, the media and charities, are not clearly covered across the ‘use of data’ consultation, including in the research and statistics proposals. We think a much clearer explanation is needed of how to grasp the issue of private sector access to data for research, explaining how new powers affect this.
- 1.7. Our initial statement also commented that privacy safeguards should be better articulated for data sharing, and our further points below address provisions for this and for transparency (these considerations are put forward for research and statistics in particular, but are also relevant across other proposals). Overarching concerns about privacy appear to affect coherence of these proposals for the legislative process, our concerns for which are set out in Section 2 below.
- 1.8. We have found support for this consultation in the following further resources, noting that the Cabinet Office’s proposals for legislation follow a number high profile calls for improved data sharing. For research and statistics in particular, we have seen the *Independent Review of Economic Statistics*,<sup>7</sup> the Science and Technology Select Committee’s *Big data dilemma* inquiry report,<sup>8</sup> the Law Commission’s scoping of data sharing between public bodies,<sup>9</sup> the findings of the Administrative Data Taskforce,<sup>10,11</sup> as well as the UK Statistics Authority recent outline of the case for change in their [policy paper](#).<sup>12</sup>

## 2. Coherence of proposals for the legislative process

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<sup>7</sup> Professor Sir Charles Bean (2016) *Independent Review of UK Economic Statistics* (PDF). Available from: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/507081/2904936\\_Bean\\_Review\\_Web\\_Accessible.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/507081/2904936_Bean_Review_Web_Accessible.pdf)

<sup>8</sup> Science & Technology Committee (Commons) (2016) ‘Big data’ is a big opportunity, but Government should tackle misuse’ (webpage). Available at: <http://www.parliament.uk/business/committees/committees-a-z/commons-select/science-and-technology-committee/news-parliament-2015/big-data-dilemma-report-published-15-16/>

<sup>9</sup> Law Commission (2014) *Data Sharing between Public Bodies: A Scoping Report* (PDF). Available from: [http://www.lawcom.gov.uk/wp-content/uploads/2015/03/lc351\\_data-sharing.pdf](http://www.lawcom.gov.uk/wp-content/uploads/2015/03/lc351_data-sharing.pdf)

<sup>10</sup> Administrative Data Taskforce (2012) *Improving access for research and policy* (PDF). Available from: [https://www.statisticsauthority.gov.uk/wp-content/uploads/2015/12/images-administrativedatataskforcereportdecember201\\_tcm97-43887.pdf](https://www.statisticsauthority.gov.uk/wp-content/uploads/2015/12/images-administrativedatataskforcereportdecember201_tcm97-43887.pdf)

<sup>11</sup> Department for Business, Innovation and Skills (2013) ‘Administrative Data Taskforce report: government response’ (webpage). Available at: <https://www.gov.uk/government/publications/administrative-data-taskforce-report-government-response>

<sup>12</sup> UK Statistics Authority (2016) *Delivering better statistics for better decisions: Why we need new legislation for better access to data* (PDF). Available from: <https://www.statisticsauthority.gov.uk/wp-content/uploads/2016/03/Delivering-better-statistics-for-better-decisions-data-access-legislation-March-2016.pdf>

- 2.1. The Cabinet Office has presented six strands of proposals for data sharing, each of which has its own illustrative clauses and impact assessment.<sup>13</sup> These address data sharing for several different purposes: improving public services, tackling fraud and debt, and improving the use of data for research and for official statistics.
- 2.2. In our view, the proposals to improve data sharing for research and statistics provide a key opportunity for discussion of the legislative framework, and an opportunity to realise significant gains. In our view there is a strong basis for these two strands ('access to de-identified data for research purposes', and 'power for the Statistics Authority to access identified data') to build upon valued existing practice, accompanied by institutional and ethical provisions and, in the case of official statistics, a professional code of conduct.
- 2.3. Importantly though, the proposals in the consultation as drafted are not clear on how new proposed Statistics Authority powers will be exercised. Paragraph 115 states 'Public Authorities may only disclose information to the Statistics Authority if they are satisfied that it is required by the Statistics Authority to exercise their functions', paragraph 116 says 'the Statistics Authority cannot use information provided from Public Authorities without the consent of the Public Authority which provided the information'. Paragraph 117 then outlines a power for the Statistics Authority to compel disclosure, but 118 says this will not apply to Crown bodies. These statements appear to contradict each other.
- 2.4. We would also like to comment on the coherence of the Cabinet Office's broader proposals. The further strands of proposals are intended to enable data sharing to improve public services, and to tackle fraud and debt. While we are not against the aims in principle, we believe the purposes may set out to share identities of citizens in order to have particular transactions with them, whereas the Statistics Authority and research proposals aim for better aggregate (non-identifiable) public information, not individual transactions. We are also not sure whether broad public acceptability has been established for these particular proposals for data sharing in ways that are well established for statistics and research. We therefore believe there is a need for caution, including in the legislative process. We conclude further below that the Cabinet Office should reconsider taking forward all proposals through a single piece of legislation:

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<sup>13</sup> Cabinet Office (2016) 'Open consultation: Better use of data in government' (webpage), available at: <https://www.gov.uk/government/consultations/better-use-of-data-in-government>

- 2.4.1. The purpose for research and statistics is to produce information about society (not about individuals), and safeguards for the privacy of individual / business data engaged in this process can be strengthened. Incentives for 'tailored public services' and to address fraud and debt may well work in the opposite direction, for example sharing identifiable data in order to have transactions with the citizen.
- 2.4.2. Arrangements made in legislation will need to harmonise with the new EU General Data Protection Regulation, which comes into force in 2018. This has some provisions that are specific to scientific research and to statistics, e.g. exemption from individual consent for personal data to be accessed in certain circumstances.<sup>14</sup>
- 2.4.3. We therefore believe that legislative proposals for de-identified research, and for the Statistics Authority to have greater powers to access data for statistics, should be clearly separated from the rest, and ideally such legislation should be proposed in a separate bill.

### **3. Cross-cutting concerns**

#### **3.1. Provisions for privacy and public trust**

- 3.1.1. While provisions for personal privacy are relatively well established for research and statistics, public acceptability is also affected by who takes part in the system, and what the data (even de-identified data) ultimately is used for. Our research into public attitudes indicated a 'data trust deficit', finding that particular uses of data have low public acceptability whereas others attract support.<sup>15</sup> Openness about the uses and the expected benefits of these uses represent an important safeguard for a public concerned about what public bodies do with their data.
- 3.1.2. The consultation asks some specific questions about the UK Statistics Authority's gateway. However we believe for public acceptability, it is important that the Statistics Authority is fully accountable to parliament on conduct of the data sharing arrangements. The new gateway proposed in the Cabinet Office consultation will enable a generalised presumption of access for the purpose of statistics, supported by a Code of Practice, but we think this

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<sup>14</sup> European Data in Health Research Alliance (2015) 'Good news for health research from trilogue talks on the data protection regulation', 17 December 2015. Available at: [http://www.datasaveslives.eu/news-resources/good-news-for-](http://www.datasaveslives.eu/news-resources/good-news-for-health-research-from-trilogue-talks-on-the-data-protection-regulation/)

[health-research-from-trilogue-talks-on-the-data-protection-regulation/](http://www.datasaveslives.eu/news-resources/good-news-for-health-research-from-trilogue-talks-on-the-data-protection-regulation/)

<sup>15</sup> RSS (2014) *Research on trust in data and attitudes toward data use / data sharing* (PDF), available from: <http://www.statslife.org.uk/images/pdf/rss-data-trust-data-sharing-attitudes-research-note.pdf>

should be subject to some sort of parliamentary oversight and tested by it. This has implications for the questions asked about the gateway's duration and process (Question 18 and Question 20.<sup>16</sup>).

- 3.1.3. In this context we would welcome provisions for transparent reporting of a number of aspects of the process: where the Statistics Authority has requested administrative data from, why it has made the request, the technical arrangements for access (whether as a direct data share to the Authority or a temporary arrangement for de-identified research) and the occasions on which this is refused. We think steps to strengthen transparency are needed to accompany the proposed shift away from setting up specific gateways with parliamentary approval for specific data shares.

### **3.2. Improving data sharing for research purposes: support data infrastructure and skills, and prevent bottlenecks**

- 3.2.1. At the level of the legislation, review will be needed to ensure that standards are harmonised with those that operate for health data, so that health data can be part of de-identified linkage for research, and to ensure that the proposed legislation is a good fit with the new EU General Data Protection Regulation.
- 3.2.2. Across the de-identified research proposals, there is also a need to build in flexibility to accommodate the development of good practice (in technological or process terms). We therefore think that our comments below are largely to be addressed in the Code of Practice, given that this can more readily be revised over time.
- 3.2.3. The premise for the de-identified research proposals is a strong system of de-identification, so that the researcher can analyse linked data without extracting, examining or identifying individual citizen data.<sup>17</sup> It is proposed that this will be overseen by the Statistics Authority. As the duties associated with such an oversight role are substantial, and as the gateway is expected to form a key part of data access infrastructure for researchers, we have concerns that there must be resources tied in to ensure that the administration works.

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<sup>16</sup> Question eighteen: Is two years a reasonable maximum period of time for the duration of a notice for the supply of data to the UK Statistics Authority for the purposes of producing National and official statistics and statistical research? Question twenty: What principles and factors should be considered in preparing the Code of Practice on matters to be considered before making changes to the processes that collect, store, organise or retrieve data?

<sup>17</sup> Here we refer to the consultation's section on 'Access to data which must be linked and de-identified using defined processes for research purposes'

There are already substantial inefficiencies in data access systems for researchers, and creation of further bottlenecks needs to be avoided.

3.2.4. To answer Q15 in the consultation, we think a cost-recovery mechanism for government departments may help support the system, but is unlikely to be enough.<sup>18</sup> The proposals should offer more certainty about resourcing and oversight.

3.2.5. Defining public good appropriately with regard to the research process:

The consultation's question 17 identifies an important need to define and judge whether research proposed is for the public good, so that it can be approved or rejected in the public interest.<sup>19</sup> Such a judgement cannot be defined generically in terms of particular research purposes or outcomes. In some cases, trusted third party linkage may work, but where linkage rates are low, access to unlinked records can also be necessary – or access to surveys. Also, new methods are being developed to enable access to data in conditions of privacy and the legislation shouldn't tie itself to one, which may be superseded. Legislation should operate at a high level in setting out the 'public good' purpose, as a matter of principle, with matters of detail delegated to the Codes of Practice.

3.2.6. The proposed Codes of practice can provide further guidance, as they can be revised over time. We think that the Cabinet Office / Statistics Authority should set out an accepted generic process by way of these. Practices that could be made standard include lay involvement of members of the general public, proportionate consideration of risk and benefit, transparency about which data shares have been permitted; and publication of the full research results obtained as a result of sharing. Standard process should set out a workable method of documenting and assuring public good from data sharing. Setting out the accepted process would also help to clarify the role of non-public bodies in the research system, and when and how their involvement is acceptable.

3.2.7. To define research processes that have appropriate regard to the public good, common understanding is needed of the work of research ethics committees, data access committees, and approved researchers. We suggest that you draw upon findings from the forthcoming independent review of the Administrative Data Research Network to inform this. They have begun to operate along the lines of the de-identified research system

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<sup>18</sup> Question fifteen: Should fees be charged by public authorities for providing data for research purposes, and if so should there be a maximum fee permitted which is monitored by the UK Statistics Authority?

<sup>19</sup> Question seventeen: What principles or criteria do you think should be used to identify research that has the potential for public benefit, or research that will not be in the public benefit?

discussed, as far as the existing legislation and government culture allows. Other administrative data research centres, eg in the devolved nations, should also inform the defined process.

#### **4. Closing comment**

- 4.1. To close, we would like to emphasise the importance of ensuring amendments to legislation are appropriate. Taken collectively, current data sharing legislation is incoherent and fragmented, but is highly necessary in underpinning what takes place. As was set out in the Law Commission's scoping review of government data sharing, there are many non-legislative barriers to making better use of government data.<sup>20</sup> Leadership and training needs to develop to change the current risk averse culture. Embedding and supporting key institutions for public trust in government data should be a matter of high priority in the government's approach to data sharing, and in development of the accompanying legislation and standards.

*FINAL RESPONSE ENDS.*

*Submitted by RSS' Policy & Research Manager on 22 April 2016.*

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<sup>20</sup> Law Commission (2014) *Data Sharing between Public Bodies: A Scoping Report* (PDF). Available from: [http://www.lawcom.gov.uk/wp-content/uploads/2015/03/lc351\\_data-sharing.pdf](http://www.lawcom.gov.uk/wp-content/uploads/2015/03/lc351_data-sharing.pdf)

## **APPENDIX 1: About the Royal Statistical Society (RSS):**

The RSS responds to this consultation as a charity and a membership organisation which focuses on the production and use of statistics and statistical research. One of our key strategic aims is to promote better use of data for the public good. This is represented most recently in our Data Manifesto, which identified 10 areas for improvement in government policy and practice. One of its key recommendations is that there should be greater data sharing for the purpose of statistics and research.<sup>21</sup> In presenting their proposals and support for an open policy making process, the Cabinet Office have provided a key opportunity for discussion of the legislative framework for this, to which the RSS has been glad to respond.

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<sup>21</sup> RSS (2014) Data Manifesto (webpage), available at: [www.rss.org.uk/manifesto](http://www.rss.org.uk/manifesto)

## APPENDIX 2: RSS' initial Statement to the Consultation

### RSS statement on the Cabinet Office consultation 'Better use of data in government'

1 April 2016

The Cabinet Office has recently launched a consultation document 'Better use of data in government' (available from <https://www.gov.uk/government/consultations/better-use-of-data-in-government>). This statement presents the Royal Statistical Society (RSS)'s initial response.

As a charity and a membership organisation which focuses on the production and use of statistics and statistical research, one of our core aims is to promote better use of data for the public good. This is represented most recently in our Data Manifesto, which identified 10 areas for improvement in government policy and practice. One of the key recommendations in the Data Manifesto is that there should be greater data sharing for the purpose of statistics and research.<sup>22</sup>

The Cabinet Office consultation document sets out proposals for new legislation that addresses data sharing in government for several purposes: improving public services, tackling fraud and debt, and improving the use of data for research and for official statistics.

We welcome and support the Cabinet Office initiative and believe clarity, efficiency and proportionality of any new data sharing legislation will be crucial to support the better use of data by government.

Below we respond to key proposals with regard to how they address UK statistics and research needs, and indicate how we believe these proposals can be strengthened.

In summary, our five key areas of comment on the proposed legislative framework are:

1. The proposals for improved **access for statistical purposes** should be strengthened to an automatic presumption of access, rather than the right to access;
2. To improve sharing and linkage of **data for research purposes**, we believe greater flexibility should be introduced, including for access to survey data, and that the proposals for research overall require clear oversight and allocation of funding. The proposals need to allow for faster and more agile access, without losing privacy safeguards;
3. We would like to see a clearer articulation of how **privacy concerns** would be met for the new proposals, especially where they do not build on existing safeguards;
4. The proposals are silent on how **health and social care data**, which are of essential interest to the research and statistical communities, will be handled;

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<sup>22</sup> Royal Statistical Society (2014) Data Manifesto (webpage), available at: [www.rss.org.uk/manifesto](http://www.rss.org.uk/manifesto)

5. The proposals should be clear on how the government wants to handle the issue of **access to data by non-public bodies**.

The paragraphs below expand on each of these points. One general point to make is that improved legislation in this area will be a necessary but not sufficient condition – culture and resources will also play an important part and must be tackled side by side with legislation.

## 1. Improved powers for the ONS to access administrative data for production of statistics

- 1.1. The findings of the *Independent Review of Economic Statistics* (the ‘Bean Review’), which the Government has fully endorsed, show the importance of greater powers for the Office for National Statistics (ONS) to improve UK statistics and understanding of our economy.<sup>23</sup>  
<sup>24</sup> As part of our *Data Manifesto*, the RSS called for legislation to be strengthened for the ONS to access the data needed for national statistics. The current framework is cumbersome and unwieldy and takes far too long to enable data access for the production and improvement of official statistics. We therefore welcome the intention stated in Cabinet Office proposals for the ONS to “access detailed administrative data from across government and businesses, to provide more accurate, frequent and timely statistics and to update how the census is managed, instead of relying on surveys”.<sup>25</sup>
- 1.2. The consultation document proposes that government departments will be given the right to provide information to ONS if they are satisfied that this is required by the ONS to exercise its functions. We fear, however, that this will not achieve the stated purpose. The Bean Review recommends as a model the arrangements that are currently in place the Office for Budget Responsibility (OBR), which gives “a right of access (at any reasonable time) to all Government information which it may reasonably require for the purpose of performance of its duty”, and says that the ONS should be similarly empowered. This should be accompanied by “an independent ombudsman (or similar) appointed to adjudicate difficult cases”.<sup>26</sup> We too believe that in the detail of the legislation, the mandate for the ONS should be strengthened so that there is a presumption of data access for statistical purposes.

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<sup>23</sup> ‘Better data access will improve economic statistics, says Bean’, *StatsLife*, 2 December 2015

<https://www.statslife.org.uk/news/2585-better-data-access-will-improve-economic-statistics-says-bean>

<sup>24</sup> Cabinet Office, HM Treasury (2016) ‘Independent review of UK economic statistics: government response’ (webpage).

Available at: <https://www.gov.uk/government/news/independent-review-of-uk-economic-statistics-government-response>

<sup>25</sup> 4, p. 3 in Cabinet Office (2016) *Better Use of Data: Consultation Paper* (PDF), Available from:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/503905/29-02-](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/503905/29-02-16_Data_Legislation_Proposals_-_Con_Doc_-_final_3_.pdf)

[16\\_Data\\_Legislation\\_Proposals\\_-\\_Con\\_Doc\\_-\\_final\\_3\\_.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/503905/29-02-16_Data_Legislation_Proposals_-_Con_Doc_-_final_3_.pdf)

<sup>26</sup> 4.154 p. 166 in Professor Sir Charles Bean (2016) *Independent Review of UK Economic Statistics* (PDF).

- 1.3. Additionally we welcome the Cabinet Office proposal that “a new power be created to broaden the scope of data that can be requested [from businesses] and allow more modern methods of data collection which can move current processes away from outmoded, burdensome and expensive surveys”.<sup>27</sup> This is in line with what has been recommended by the Bean Review, by the Science and Technology Committee, and what has already been enacted in other countries such as Canada. The legislation should enable safe statistical processing of more different types of business data, for the production of aggregate statistics.

## 2. Support for secure access to de-identified linked data for research projects

- 2.1. The consultation sets out proposals to ease access to de-identified government data for the purpose of research, by setting out standards for accredited research, researchers, and facilities. Research that explores public attitudes has shown substantial support from the public for data to be used for scientific, social or statistical research, with an intended public benefit, and with privacy safeguards in place.<sup>28, 29, 30</sup> The proposed legislation would standardise what in many cases are already the type of data protection that research approvals panels seek, to support ethical research that protects the identities and privacy of people during and after the research process.
- 2.2. We welcome the proposal that government departments should share and link more data for research through well-protected arrangements. We think however that Departments may also need stronger incentives to take part. Delays to data access approval, even after research bids and projects have been approved, are a drain on public funding for researchers and for their funders. The Cabinet Office are consulting on their proposal that Departments charge a fee to the applicant, on a cost-recovery basis, in return for supplying data for linkage. We are not convinced that this is the right model, especially if it creates more of an administrative burden in the system. We note the governance role that will be played by the UK Statistics Authority and we welcome that there will be an oversight body in this area, but we note it must be adequately resourced for this function.

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<sup>27</sup> 14, p.4 in Cabinet Office (2016) Better Use of Data: Consultation Paper (PDF), Available from:

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/503905/29-02-](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/503905/29-02-16_Data_Legislation_Proposals_-_Con_Doc_-_final__3_.pdf)

[16\\_Data\\_Legislation\\_Proposals\\_-\\_Con\\_Doc\\_-\\_final\\_\\_3\\_.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/503905/29-02-16_Data_Legislation_Proposals_-_Con_Doc_-_final__3_.pdf)

<sup>28</sup> ESRC (2014) ‘Public dialogues on using administrative data’ (webpage), Available at: [www.esrc.ac.uk/public-engagement/public-dialogues/public-dialogues-on-using-administrative-data/](http://www.esrc.ac.uk/public-engagement/public-dialogues/public-dialogues-on-using-administrative-data/)

<sup>29</sup> ‘RSS research finds data trust deficit, with lessons for policymakers’, *StatsLife*, 22 July 2014. Available at:

<https://www.statslife.org.uk/news/1672-new-rss-research-finds-data-trust-deficit-with-lessons-for-policymakers>

<sup>30</sup> ‘Public supports sharing health data for research, survey says’, *StatsLife*, 14 March 2016. Available at:

<https://www.statslife.org.uk/news/2721-public-supports-sharing-health-data-for-research-poll-says>

- 2.3. It is important that the legislative framework has enough flexibility for researchers. The proposals being consulted on go into some detail about the Trusted Third Party model for de-identifying linked administrative data. However one opportunity which is not currently addressed by the proposals (and which therefore appears unduly limited) is the possibility of linking administrative data with survey data. From our perspective this is a key opportunity to be realised. Administrative data is not designed for research purposes, and the most fruitful research will often come from being able to link it with surveys.
- 2.4. We also believe in general terms that there should be no long-term 'lock-in' to the Trusted Third Party model, and we support that it will be implemented by a statutory Code of Practice that should be reviewed and updated with ministerial approval. Scope for revision is important so that the legislation does not build in obsolescence. We are in a period of significant technological change, and new ways to manage safe data linkage may evolve. The legislation should establish the broad principles of research approval rather than making detailed prescriptions.
- 2.5. We also welcome that Cabinet Office proposals will not sweep away any of the pre-existing legal gateways for data sharing. This reflects that there are areas where existing access arrangements are working, and need not to be disturbed. For example devolved administrations of the UK are noted as areas where further discussions of approved systems for de-identified data linkage are taking place.

### **3. Articulation of privacy safeguards**

- 3.1. Privacy safeguards in the Cabinet Office's proposed legislation include a criminal offence for unlawful disclosure of data, by which those found guilty will face either a fine or up to two years' imprisonment. In addition, statutory Codes of Practice will set out if, how and when data can be disclosed. Although we believe these provisions will be helpful, it is unclear to us how they will satisfy privacy concerns and we believe they should be spelled out in further detail.
- 3.2. This could usefully be done by explaining the consequences of the proposals in relation to the Information Commissioner's Office advice to the Law Commission which stated that "the "recipe" for data sharing standards, such as security, transparency, and privacy impact assessments, [should be] broadly consistent, and should contain meaningful safeguards for individuals, especially in light of the different levels of sensitivity and privacy impact that different types of data might have."<sup>31</sup>

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<sup>31</sup> 11.7 p. 167 in Law Commission (2014) *Data Sharing between Public Bodies: A Scoping Report* (PDF).

#### 4. Integration of health and social care data

- 4.1. Another concern we have is that it is not clear if and how health and social care data can be linked with other data for research purposes. This is an area where the scope of the Cabinet Office's interventions has been strictly limited, as health data is subject to separate legislation and has been under review by Dame Fiona Caldicott. It is hugely important that standards for research emerging from the Cabinet Office proposals are integrated with those that will be brought in place for patient records. Many of the most socially beneficial research questions seek to link health and care data with other data domains, such as conditions of employment and welfare, education, and the environment. This was represented under the tagline 'data saves lives' as the new EU General Data Protection Regulation was being debated, in a campaign that made clear that data linkage across health and other domains supports hugely valuable research for public benefit, and needs to be workable and permitted.<sup>32</sup>

#### 5. Data access for non-public bodies

- 5.1. Non-public bodies engaging in research, such as private companies, the media and charities, are not clearly covered by the proposals. We do not in general terms think that a different set of rules should apply to private actors, as compared to public bodies. Our own research identified that although research uses are relatively well regarded by the public, government needs to tread carefully for public trust in the uses data may be put to by non-public third parties.<sup>33</sup> We have welcomed important insight into the nuance of public views on this, in findings that have recently been obtained by the Wellcome Trust.<sup>34</sup> We would therefore welcome a clear statement of how the government intends to grasp the issue of private sector access to data.

*Background and further resources to this statement are included at 1.8 of the final response.*

APPENDIX ENDS.

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<sup>32</sup> EHDA (2015) *Data Protection Regulation and health research: The issues explained* (PDF). Available from: <http://www.datasaveslives.eu/media/1178/data-saves-lives-position-paper-october-2015.pdf>, and case studies at <http://www.datasaveslives.eu/case-studies/>

<sup>33</sup> Royal Statistical Society (2014) *Research on trust in data and attitudes towards data use / data sharing* (PDF), Available from: <http://www.statslife.org.uk/images/pdf/rss-data-trust-data-sharing-attitudes-research-note.pdf>

<sup>34</sup> Ipsos MORI SRI (2016) *The One-Way Mirror: Public attitudes to commercial access to health data: Report prepared for the Wellcome Trust* (PDF). Available from: [http://www.wellcome.ac.uk/stellent/groups/corporatesite/@msh\\_grants/documents/web\\_document/wtp060244.pdf](http://www.wellcome.ac.uk/stellent/groups/corporatesite/@msh_grants/documents/web_document/wtp060244.pdf)