

# Data Sharing Review

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## Consultation paper on the use and sharing of personal information in the public and private sector

### List of questions for response

We would welcome responses to the following questions set out in this consultation paper. Please follow the question order as set out in the consultation paper, leaving a blank response box for any questions not answered.

Please email your completed form to [contact@datasharingreview.gsi.gov.uk](mailto:contact@datasharingreview.gsi.gov.uk)

Alternatively you can send a hard copy response to:

**Data Sharing Review Secretariat**  
**5.26 Steel House**  
**11 Tothill Street**  
**London**  
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Thank you.

### Section 1: Background

#### Question 1

Please explain what your interest in information sharing is.

If you have an active involvement in personal information sharing, we would be grateful for the following information:

- What kinds of personal information do you collect, hold and share?
- How do you collect, hold and share such personal information?
- For what purposes do you collect, hold and share such personal information?

Comments:

The Office for National Statistics (ONS) collects information about people, households and businesses for statistical purposes only. Information is either collected through surveys (voluntary or otherwise) or disclosed through a legal gateway from an administrative source. ONS currently has very limited statutory powers to share this information. There are powers in the Statistics of Trade Act 1947 (delegated by the Chancellor of the Exchequer) that allow information collected under that Act to be shared with other government departments.

ONS has long been interested in the sharing of personal information, whether related to an identifiable person or a body corporate, for statistical purposes. Access to such information

from administrative or other sources through data sharing is increasingly seen as essential for the development of better information to support policy formulation, monitoring and review. The 2005 Report of the Government Statistical Service's (GSS) Working Party on Data Transfer recognised the need for legislative change and improved guidance on practical issues and highlighted the unmet demand for personal information to improve statistical analysis and research, the quality, relevance and efficiency of National Statistics and the effectiveness and efficiency of government service delivery.

The Statistics and Registration Service Act 2007 establishes a new body, the Statistics Board, with a statutory responsibility to promote and safeguard the production and publication of official statistics that serve the public good. The Board is the legal successor to ONS and will come into being on 1 April 2008. At the core of the Act lies the Board's obligation to protect the confidentiality of the personal information it holds; contravention of this obligation incurs a criminal penalty. The 2007 Act also includes provisions that allow the making of regulations to permit a public authority to share personal information with the Board for statistical purposes and to permit the Board to do likewise with a public authority.

In addition to the 2007 Act, there are existing legal gateways (eg s.5 of Census Act 1920, s.270 of the National Health Service Act 2006) and the class actions held by ONS under s.60 of the Health and Social Care Act 2001 that cover the sharing of data between ONS, the Registrar General and the NHS. Some of these gateways will change on 1 April 2008 with the coming into force of the 2007 Act and the creation of the Statistics Board.

## **Section 2: Scope of personal information sharing, including benefits, barriers and risks of data sharing and data protection**

### **Question 2**

What in your view are the key benefits of sharing personal information to a) individuals and b) society? Please provide examples.

Comments:

(a) Statistics are largely produced from data collected directly from households or businesses. Data sharing can contribute significantly to reducing the burden on these respondents. This dovetails with Human Rights legislation which requires government to respect the private life of its citizens and not to interfere unnecessarily and too often by, for example, intrusive data collections.

(b) The benefits to the society are better policy making and a reduction in the costs of data collection. The statistical benefit of access to individual record level data is a more flexible system and statistical source base to inform policy implementation, development and monitoring. Administrative records often provide coverage of the whole population of interest, whereas surveys only cover a small sample. Consequently access to such records through data sharing would facilitate the production of comparable information from the national to the local level. By linking individual records, statisticians will be able to understand more fully complex relationships between issues such as crime, education and health for a range of geographical areas.

There is a requirement across government for accurate and timely statistics to support policy

formulation and management, supplemented by a growing need for regional and local level data. There is enormous potential to use data that are already collected by government to meet these requirements and as a result the need for, and importance of, data sharing is widely recognised. The sharing of data will mitigate the high cost of meeting these requirements through traditional surveys and censuses and help deal with the increasing difficulties associated with maintaining high response rates. At the same time data sharing will improve the availability of information at small area level and support work designed to meet demands for increasingly sophisticated performance measures and cross-cutting indicators. Data sharing provides a cost-effective option and can contribute significantly to reducing the burden placed on respondents (both individuals, households and businesses) by ensuring that individual data items are collected once but used many times. By making better use of information that is already available through data sharing, linking and matching the Statistics Board should be able to develop and improve the quality and range of official statistics.

### **Question 3**

What in your view are the key risks of sharing personal information to a) individuals and b) society? Please provide examples.

Comments:

ONS holds personal information for statistical purposes only. No identifiable information is published and access to personal records strictly controlled. Risks to individuals arise only if confidentiality is not protected ; contravention of an obligation to protect confidentiality incurs a criminal penalty. This position is especially acute in the case of census information where successive Governments have reiterated the policy of keeping that information confidential for 100 years in order to comply with the undertakings given to respondents at the time of data collection.

Another risk would be that information that is collected for one specific purpose is later used for a purpose incompatible with the original intent or for a use beyond that which the supplier has consented or expected. This risk is managed in ONS' Survey Charter and in the pledges made to respondents to our surveys.

There are also risks to society from inaccurate information. Accurate and relevant data to inform debate is a vital ingredient for good policy making, but equally poor data can lead to poor and ill informed policy making.

However the risks of sharing information do not outweigh the benefits provided the appropriate checks and balances are in place to consider any request and to ensure that the data are held securely and used for the purposes for which they are supplied.

### **Question 4**

As mentioned in the introduction, there are wide variations in the scope and methods of personal information sharing. What scope and what methods, in your view, pose the greatest opportunities or risks? Please explain the reasoning behind your response.

Comments:

### **Question 5**

Please provide examples of where, in your view, the public authorities hold too much data or not enough personal information, and the reasoning behind your response.

Comments:

### Question 6

Please provide examples of where, in your view, private sector organisations hold too much personal information or not enough personal information, and the reasoning behind your response.

Comments:

### Question 7

Please provide examples of cases where you believe the sharing of personal information between two or more bodies would be beneficial, but where it is not currently taking place.

Please explain as fully as possible why information is not being shared, detailing what the barriers to the sharing of personal information are – e.g. legal, cultural, financial, institutional – and how these barriers can be overcome.

Comments:

If ONS is to respond to the increasingly complex needs of Government the sharing of record level data on individual persons, households or businesses will be essential. Both the Allsopp 'Review of Statistics for Economic Policymaking' [ [http://www.hm-treasury.gov.uk/consultations\\_and\\_legislation/allsop\\_review/consult\\_allsopp\\_index.cfm](http://www.hm-treasury.gov.uk/consultations_and_legislation/allsop_review/consult_allsopp_index.cfm) ] and the 'Report of the Inter-departmental Task Force on Migration Statistics' [ <http://www.statistics.gov.uk/statbase/Product.asp?vlnk=14731> ] underlined the need for, and importance of, making better use of data sharing, linkage and matching.

Data sharing would facilitate the development of new statistics, more sophisticated performance measures and cross-cutting indicators as well as the improvement of existing outputs. In particular, the availability of data held by HM Revenue and Customs, the Department for Work and Pensions, the Home Office and the Department for Children, Schools and Families would be beneficial and support the improvement of population, migration, social, business and economic statistics. The examples outlined below illustrate the multiplicity of benefits likely to arise from the sharing of personal information between ONS, Government departments and other public bodies for statistical purposes.

#### Example One: Population and Migration Statistics

It is increasingly important to have good quality statistics on the magnitude of migration to and from the United Kingdom. Migration has a direct impact on the size and age structure of the population and is one of the key components of population change. Information on migration is essential for the derivation of the mid-year population estimates. In addition, trends in migration are required for population projections.

Population statistics are used to allocate resources, support policy development and review as well as plan and deliver services. The Statistics Commission has estimated in the context of developing estimates of internal and international population migration that around £1 billion might be misallocated due to inadequate population statistics. In addition, statistics on the size, composition and duration of stay of immigrants and emigrants are required to

address government and business planning at both national and local levels, evaluate the social and economic impact of migration and inform policy on immigration control.

There is currently no single source of data that can be used to measure migration flows or monitor changes in patterns of migration. ONS does not have complete information from any single source on when people leave the country. By bringing together different sources, it is possible to build up a more complete statistical picture of who is in the country and how long migrants stay here. Obtaining record level data from a number of administrative sources, including systems used for monitoring entry and departure, tax and benefit records, will facilitate a better understanding of the extent, nature and impact of migration and its implications for the size and structure of the UK population.

Moreover, effective linkage and matching of individual records will open up new areas for research and analysis, helping to improve our understanding of the complex changes affecting individuals and the differences between initial intentions (at the time of entry) and subsequent outcomes. In this way we should be able to provide breakdowns of long and short-term migration by duration of intended or actual stay as well as consider patterns of employment and childbearing. It is only by comparing results from a number of separate sources that it will be possible to produce authoritative statistics on migration and maintain the integrity of our population estimates and projections.

Key benefits likely to arise from the sharing of data include:-

**Better Policy Formulation and Review** - the availability of more accurate migration and population estimates will contribute to better evidence-based policy making including monetary and fiscal analysis, workforce planning and border control.

**Better Resource Allocation and Service Provision** - more reliable population estimates will provide a better basis for assessing resource requirements, allocating grants and other types of funding, including regional aid, to the areas of greatest need. In addition, the availability of more accurate estimates will contribute to the evaluation and review of service take-up and delivery.

**Better Evaluation and Analysis** - better information on population and migration will provide a sound basis for measuring and monitoring demographic and socio-economic changes, understanding variations in educational and employment opportunities, the nature and extent of disadvantage and the impact of discrimination. Bringing together record level data from a number of separate sources will support cross-cutting analyses, the derivation of indicators and research.

### **Example Two: Economic and Business Statistics**

The Government requires comprehensive, accurate and timely information to manage the economy, to encourage enterprise and innovation as well as to understand the nature and impact of structural and other changes. ONS is required to meet demands for increasingly sophisticated measures of economic performance to support monetary and fiscal policy, to understand labour market requirements, to promote growth, improve economic performance and productivity, to overcome inequalities, to encourage innovation and enterprise and ensure that Government funding is distributed to the areas of greatest need.

Access to a range of administrative sources, including data collected by HM Revenue and

Customs and the Department for Work and Pensions will improve both national and regional statistics, reduce the burden on data suppliers, most notably small businesses, and generate significant cost savings. In particular, the availability of tax data for individual businesses would enable ONS to improve efficiency and value for money in its data collection and increase quality by extending coverage of small businesses.

Key benefits likely to arise from the sharing of data include:-

**Better Policy Formulation and Review** - the availability of more accurate economic and business statistics will contribute to better evidence-based policy making, including monetary and fiscal analysis, and to work designed to increase growth in the regions, deal with inequalities, improve productivity and take account of the contribution of different economic sectors. Better information could inform decisions relating to economic performance, changes to the labour market, low pay and the level of the National Minimum Wage.

**Better Statistics** - access to a range of record level information from a number of sources should improve the coverage, relevance and quality of economic and business statistics. For example, extending access to administrative data, primarily those held by HM Revenue and Customs, would enable ONS to:-

- improve the quality of estimates used to construct the National Accounts;
- expand coverage of small businesses;
- improve industry detail; and
- produce better regional estimates and take forward recommendations highlighted by the Allsopp Review.

**Reduced Burden** - if ONS had access to data held by HM Revenue and Customs it would open the way to reduce the burden on small businesses because they would potentially no longer need to complete a number of survey forms as well as tax returns. Access to administrative data would enable ONS to adjust current survey practices and change medium and long term survey planning.

**Reduced Costs** - better use of a range of tax data would help to prevent compliance costs becoming a barrier to improvement in key economic and business statistics. For example, it is estimated that access to all data from VAT returns would produce significant annual savings to ONS and to businesses.

Such sharing of data would comply with the simplification plans endorsed by the former Prime Minister and guidance produced by the Cabinet Office as well as general requirements outlined in the Hampton Report.

**Please explain as fully as possible why information is not being shared, detailing what the barriers to the sharing of personal information are - e.g. legal, cultural, financial, institutional - and how these barriers can be overcome.**

At present it is not possible for ONS to access data held by other Government departments or public agencies unless there is an explicit legal gateway. Despite recognising the need for, and importance of, data sharing ONS has been unable to make significant progress because of existing legal constraints.

After 1 April 2008 specific powers in the Statistics and Registration Service Act 2007 (the 2007 Act) should facilitate the sharing of data for statistical purposes.

Even if legal obstacles are removed, the sharing of personal data, especially sensitive information, may not be acceptable because of underlying concerns about confidentiality and security. These matters are inextricably linked to fundamental issues such as public acceptability and trust which underpin the reputation and integrity of ONS. In many cases the legal right to share data is only the first step and any application will be subject to detailed scrutiny including comprehensive security checks and clearance as well as review by specially constituted release panels or ethics committees. Obligations to respondents, confidentiality pledges or other guarantees would be paramount.

#### **Question 8**

Please provide examples of cases where you believe that personal information is being shared between two or more bodies, but where this should not be taking place.

Please describe the information-sharing concerned and why you believe it should not be taking place, including the risks involved in such information-sharing.

Comments:

### **Section 3: The legal framework**

#### **Question 9**

In your view, how well does the DPA work? Please outline the DPA's main strengths and weaknesses and any proposals for changes you would like to see made, including suggestions for their implementation.

Comments:

#### **Question 10**

In your view, how well do public authorities and private organisations adhere to the second principle of the DPA? How valuable do you believe the second principle is? Please provide examples and the reasoning behind your response.

Comments:

#### **Question 11**

What technical, institutional or societal barriers stand in the way of the effectiveness of the DPA? Please provide examples.

Comments:

#### **Question 12**

What further powers, safeguards, sanctions or provisions do you believe should be included in the DPA.

Comments:

#### **Question 13**

Are there any other aspects of UK or EU law (such as EU Directive 95/46/EC) that impact positively or negatively on data sharing or data protection? Please provide examples.

Comments:

European statistical law (Regulation 1588/90, Regulation 322/97, and various sectoral regulations for statistics to deliver by the Multiannual Statistical Work Programme) makes provisions for the exchange of confidential data for statistical purposes within the European statistical system. Some sectoral regulations contain an obligation to provide confidential data to Eurostat, the statistics office of the Commission. A new framework statistical law is currently going through the Co-Decision procedure. This proposal refines the provisions for sharing data for the development, production and dissemination of European Statistics. Broadly speaking these provisions enable the Commission to bring an act of Community law to permit, or require, the transmission of data for specified statistical purposes. They are necessary for the efficient production of good quality, timely and relevant statistics to underpin the activities Union. These regulations have a direct effect in the UK.

#### **Question 14**

Are there any statutory powers unavailable that would enable better and more secure sharing of personal information– for example for identity authentication purposes – between a) public authorities and b) public authorities and private organisations? If so, what are they?

Please provide examples and any steps you believe could be taken to improve matters.

Comments:

#### **Question 15**

Are there any parts of the legal framework that place an unreasonable burden on business? Please provide examples.

Please outline your proposals for streamlining the legislation to ensure that such burdens are minimised.

Comments:

The ability to share data would make a positive and significant contribution to ONS' ability to reduce the burdens imposed on business by surveys.

### **Section 4: Consent and transparency**

#### **Question 16**

Is it clear whether and when you need individuals' consent to share information about them? Are you clear about the form that consent should take? Please provide examples.

Please provide details of any initiative you have been involved in that has been based on consent.

Comments:

ONS handles information that is collected voluntarily through its surveys. No identifiable data collected in those surveys is able to be shared without the consent of respondents.

ONS also deals with patient data within the constraints of the Care Record Guarantee (having consent for sharing, obtaining s60 cover or the use of anonymisation or pseudonymisation).

### **Question 17**

What, if any, barriers would a requirement for gaining consent create to the sharing of personal information? Please explain your reasoning.

Comments:

Administrative costs of obtaining consent from individuals after data had been collected would be prohibitive, and would negate most of the savings made by data sharing. ONS' preferred approach is to make clear to respondents in our survey information the uses to which data collected will be put.

### **Question 18**

Do you have any suggestions on how to make the sharing of information more transparent? For example, should individuals be given strengthened access rights? And if so, how? Should organisations be expected to do more to explain their use and sharing of personal information to the public? And if so, how?

Comments:

Under our s.60 Class Actions, ONS has been involved with others in producing several leaflets to make the public more aware of the uses of their cancer or congenital anomaly data (and the benefits of this data sharing). Where appropriate ONS encourages researchers making contact with subjects to ensure they are aware of how any data will be used and processed (e.g. cohort and other follow-up studies).

### **Question 19**

How can we best ensure that information sharing policy is developed in a way that ensures proper transparency, scrutiny and accountability?

For example:

In your view, how valuable is the Information Commissioner's recently published Framework code of practice for sharing information?

In your view, how valuable are privacy impact assessments along the lines announced by the Information Commissioner on 11 December?

Comments:

The ICO Framework code of practice is a useful starting point for an organisation whose primary interest in information sharing is for statistical purposes. The new legal framework set out in the 2007 Act will inform and guide the Statistics Board in these matters. Brought together, these two things will ensure compliance and improve public trust. It is expected that the Statistics Board will want to publish its approach to information sharing so that it is clear to its customers, suppliers, partners and staff.

## **Section 5: Technology**

### **Question 20**

What impact in your view have technological advances had on the sharing and protection of personal information? Please provide examples.

Comments:

### **Question 21**

Should the law mandate specific technical safeguards for protecting personal information?

For example, should there be an explicit requirement that all personal information held on portable devices be encrypted to a particular standard?

Comments:

There is a perception that the law does not keep pace with mandated technology as it is regularly overtaken by new principles, designs or usage. The approach in the DPA – to mandate compliance with current best practice - is the minimum required. An organisation can then keep up to date as a standard or choose to adopt its own higher standard where such a solution is justified.

### **Question 22**

How, in your view, could 'privacy enhancing techniques', such as the anonymisation or pseudonymisation of personal information, help safeguard personal privacy, whilst facilitating activities such as performing medical research?

Is sufficient advice about the deployment of such techniques available? Are you confident about using them? What are the barriers to using them?

Comments:

ONS has considerable experience in record linkage and in techniques for separating personal identifiers from variables needed for analysis. However there are considerable limitations to achieving anonymisation or pseudonymisation of complex datasets (e.g. longitudinal data) without severely compromising their value for statistics and research. For this reason, we have developed the concept of "approved researchers" and special licences - to achieve a balance between reducing identifiability to the minimum and retaining analytic capability (see answer to Q27).

Moreover, ONS has experience of using statistical disclosure control (SDC) techniques to create anonymised microdata files. Used in combination with different access arrangements such as our own Virtual Microdata Laboratory (VML) these techniques can provide users with data that can be used for a wide range of research. Stricter licensing/access arrangements means less reliance on the SDC methods. We do not currently produce totally public microdata files, there is always some licence in place. In order to produce a safe public use file the SDC methods would result in a file that would not be able to facilitate detailed research.

ONS has expertise in the development and use of methods for assessing the risk of microdata files and SDC techniques used to protect microdata files. We ensure we keep up to date on research and new methods in the field. We are confident in applying the

techniques for anonymisation. The majority of files are protected by reducing the detail of particular variables or suppressing records/variables. In some cases perturbative methods are implemented. Some barriers exist to the use of these more complex methods for regular outputs in terms of time and resources.

On its inception in 2004 the VML was subjected to a full external security review. This described the VML and its procedures as "meeting or exceeding best practice in almost every area...The approach to address of release controls is especially disciplined and effective and would considerably exceed best practice".

## **Section 6: International comparisons**

### **Question 23**

Are you aware of any jurisdictions whose legal framework for sharing and protecting personal information contains features that could be useful in a UK context? Please provide examples.

Comments:

The Republic of Ireland has very powerful law for exchanging data for statistical purposes. See articles 30 and 31 of their own Statistics Act 1993. (<http://unstats.un.org/unsd/dnss/docViewer.aspx?docID=295#start>). Most statistical laws in other countries, like the Statistics and Registration Service Act 2007 in the UK, contain strict prohibitions on the disclosure of personal data and the use of that data for non-statistical purposes. European statistical law requires that member states provide for the necessary protection in law of statistical data from wrongful disclosure and use for non-statistical purposes.

The Scottish Freedom of Information Act has an excellent provision for the protection of Census and personal health information. Both types of data are expressly exempt from Freedom of Information requests for 100 years.

### **Question 24**

Do you have any international examples of good practice in the sharing of personal information that could or should be adopted by the UK?

Comments:

The Scandinavian countries combine their administrative registers of the population for statistical purposes, in place of a conventional census. There are statistical advantage and disadvantages for this approach. Nevertheless, in many European countries there is a presumption that population and business registers should be available to the central statistics office for national statistics purposes. The use of administrative data for statistics is, in many countries, assumed, and it can be argued that other jurisdictions in the EU have implemented the provisions in the EU data protection directive more positively from a statistics and research perspective than is the case in the UK. For example, Article 11(2) of the Directive expressly provides for relief from the obligation to inform respondents after the event of data collection about the re-use of their personal information for statistical purposes.

The UK DPA does not carry relief from the 1st data protection principle for statistics in the same express way.

**Question 25**

Do you have any knowledge of jurisdictions that have adopted a particularly permissive or restrictive approach to sharing personal information? What have the consequences of this been?

Comments:

**Question 26**

Are you aware of significant differences in public attitudes to the sharing of personal information in other countries? Please provide examples and an explanation for why you believe this to be the case.

Comments: See Above

**Section 7: Additional questions**

**Question 27**

Are there any additional issues on the sharing of personal information and protection of personal information that this review should be considering?  
Do any of these issues apply specifically to your sector?

Comments:

A very useful concept in the Statistics and Registration Service Act 2007 is the provision for 'Approved Researchers' to access confidential data when certain criteria are met. ONS considers this to be a very useful design for a gateway. It acknowledges that what can matter most for data security is not the design of the data, but the competencies of the user. ONS is pleased to be able to provide personal data to a researcher who meets the criteria, has reason to use such information and is able to comply with the Act's confidentiality provisions. This is preferable to law that prohibits sharing by reference to data of a particular type (such as personal data).

**Question 28**

Please set out any additional suggestions or observations you have that you believe will be of assistance to the review.

Comments: