

Data Sharing Review

A consultation paper on the use and sharing of personal information in the public and private sectors (12.12.07).

1.0 Introduction

1.1 The government requested an independent Data Sharing Review to consider whether there should be any changes to the way the Data Protection Act 1998 operates and the options for implementing any changes. The review is being undertaken by Richard Thomas, the Information Commissioner and Dr Mark Walport, Director of the Wellcome Trust. The following summary is a list of the consultation questions and answers to these questions.

2.0 Summary

2.1 Section 1: Background

2.2 Question 1

Please explain what your interest in information sharing is.

2.3 Information sharing internal and external to North Yorkshire County Council.

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

3.1 Question 2

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

3.2 Sharing personal information appropriately enables North Yorkshire County Council to better fulfil its statutory responsibilities which increasingly requires partnership working. Proactive partnership working can only take place if information is shared.

3.3 Question 3

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

3.4 Key issues are where information is shared outside of legislation and/or formerly agreed information sharing frameworks without appropriate information governance arrangements in place i.e. Data Security arrangements in agencies. Reliance on electronic data-technology.

3.5 Question 4

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.

- 3.6** Guidance from different government departments on information sharing does not always advise on how information can be shared with the appropriate safeguards in place. An example of this is guidance from the Department of Health on the Partnerships for Older People initiative in relation to case finding. Case finding is a way of working preventatively with vulnerable people. The issue here is being able to identify vulnerable people within Health, Adult Social Care and Housing in order to ascertain if they qualify in order to be offered any services. Locally arrangements have been put in place for this utilising pseudonymisation of personal information. This 'privacy enhancing technique' is referred to in Question 22. It would be helpful if there were national guidance on utilising this technique in relation to case finding and other similar preventative approaches to ensure consistency.

Another example of this is information resulting from inspection reports which have given examples of involving voluntary agencies in the Single Assessment Process (SAP) for older people.. However, guidance on consent in relation to the voluntary sector being involved in SAP has not yet been issued. Although a national consultation exercise has recently considered this issue and hopefully some guidance will be forthcoming on this. Some national guidance on consent in relation to case finding and the involvement of voluntary agencies would help to ensure consistency in dealing with these issues.

Electronic systems provide the greatest opportunities to share information but without the proper safeguards pose the greatest risks. The national framework would be helpful in order to co-ordinate and integrate (where appropriate) the various national electronic systems utilised by various agencies which are the Integrated Children's System, contact point, Common Assessment Framework for Children and the SAP Common Assessment Framework for Older People (this may be extended to include vulnerable people from the age of 18) and the NHS Care Records Service. This framework would ensure that agencies could share information where they have cases in common including transitions issues where young people are moving into adult services.

The former Association of Directors of Social Services proposed that a national framework for these electronic systems should be developed. Recently a small pilot has commenced in relation to the integration of Health and Adult Social Care Records which hopefully will contribute to the development of a national framework. This framework should include satisfactory information requirements in the light of the guidance from the Information Commissioner in November 2006 as a result of concerns in relation to children's databases and also recent further guidance on encryption.

3.7 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.

- 3.8** No specific examples but our view is that both internally and externally in public authorities information should be shared appropriately as information isn't always shared when it should be shared. There is a need to strike a balance between knowing what information there is and what needs to be shared.

3.9 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.

3.10 No specific examples but see also answer to Question 4. In relation to voluntary agencies it would be useful to have national guidance on information sharing, on consent and contractual arrangements where specific collections of data are required by public authorities for their financial and performance management requirements.

3.11 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 – eg legal, cultural, financial, institutional – and how these barriers can be overcome.

3.12 Single Assessment Process guidance is not clear on whether voluntary sector bodies involved in the assessment or provision of services can be included in the e-systems of data collection inhibiting full partnership.

3.13 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.

3.14 No comments.

4.0 Section 3: The legal framework

The Data protection Act (DPA) regulates the processing of information, including its obtaining, holding, use and disclosure.

The second principle of the DPA is as follows:

“Personal data shall be obtained only for one or more specified and lawful purposes and shall not be further processed in any manner incompatible with that purpose or those purposes”.

4.1 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.

4.2 The DPA’s main strengths are its ethical and information security requirements. Its main weakness is that for some people it seems cumbersome, complex and not readily understood. It would help to overcome this if national practice guidance could be produced on all sections of the DPA. This practice guidance could include the recent publication of the guidance produced by the Information Commissioner and proposals following the consultation on the Data Sharing review.

4.3 Question 10

In your view, how well do public authorities and private organisation 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.

4.4 In some cases the second principle of the DPA can be open to interpretation and cause confusion. This principle is felt to be extremely valuable and should not be lost. The development of national practice guidance on the DPA could include guidance on the use of this principle. No specific examples.

4.5 Question 11

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

4.6 Some technical and institutional difficulties have been referred to above in the answer to Question 4. In the Department of Health Consultation on Commissioning earlier in 2007, on one of the consultation questions was 'Would it be helpful for the Department of Health to work with other government departments and national stakeholders to develop a set of common principles to help underpin local agreements?' It is felt this question is equally valid here as authorities, health trusts etc use different incompatible electronic systems, different agencies and organisations also use different standards of data management which are being applied to the various electronic systems they are using which prevent these systems being linked up. It would be helpful if the Information Commissioners Office could also be involved with the Department of Health and other government departments and national stakeholders on information sharing requirements common to them all. See also the answer to Question 4 above in relation to the proposal to have a national framework in order to help 'join up' various electronic systems.

4.7 Question 12

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

4.8 It would be useful to have more stringent penalties in place for non-compliance with the DPA.

4.9 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.

4.10 No comments.

4.11 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.

4.12 At present there are no identity authentication arrangements in place and hence it would be helpful for these to be in place to ensure there are national consistent appropriate arrangements in place.

4.13 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.

4.14 No.

5.0 Section 4: Consent and transparency

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

5.2 It is clear when consent is required in an individual's case. North Yorkshire County Council does have an inter-agency 'General Framework for Sharing Information' in place which is based on written consent although for example, the Youth Offending Team can rely on their statutory requirements not to obtain written consent where they do not feel it is appropriate. There are a number of inter-agency information sharing protocols in place which do include a requirement to obtain written consent as a matter of good practice. Some example of these protocols are the Single Assessment Process for older people, the Integrated Learning Disability Teams (both these protocols are with adult social care and health) and the prevention of homelessness for 16/17 year olds, care leavers and intentionally homeless families with children's social care and the 7 district and borough councils in North Yorkshire.

Where it is more difficult to obtain consent is in specific initiatives where these concern groups of individuals, for example where the Department of Health advise that numbers of assessments and services can be counted but they do not advise on the individuals consent to include their details on an adult social care electronic database. Arrangements have been put in place locally to obtain this consent but it would be useful for the Department of Health and Information Commissioner to provide guidance on consent in these circumstances to ensure a consistent approach.

5.3 Question 17

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

5.4 See answer to Question 16 above.

5.5 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?

5.6 Yes, it would help to give individuals strengthened access rights which could be included in guidance to the DPA and guidance to agencies and organisations. Yes, organisations should do more to explain their use and sharing of personal information to the public which is supported by Local and Central Government. In the answer to Question 4 above it refers to how electronic systems designed by different agencies are not 'joined up' in order to share information more effectively.

5.7 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 personal information (http://www.ico.gov.uk/upload/documents/library/data_protection/detailed_specialist_guides/pinfo-framework.pdf)?

In your view, how valuable are privacy impact assessments along the lines announced by the Information Commissioner on 11 December (www.ico.gov.uk)?

5.8 The Information Commissioner's recently published guidance on information sharing is helpful and includes requirements to help focus on the individual to ensure they do not suffer distress as a result of their information being shared. Privacy impact assessments are also helpful in relation to this. It would be useful if the information on privacy impact assessments on the internet could be printed off to ensure easier reading and use.

In order to ensure that information sharing policy is developed appropriately it would be useful to have a 'joined up' approach to this with Local and Central Government and the private and voluntary sectors.

6.0 Section 5: Technology

6.1 Question 20

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

6.2 The impact of technological advances has had both negative and positive effects. The negative effects can include where there is a lot of data which can be stored on a Compact Disc making it easier to misplace than the equivalent paper based information. The recent national child benefit information on a CD that went missing is an example of this. This incident evidences the necessity of having good information governance requirements in place which are complied with. This incident may have occurred

because encryption arrangements were not in place or if they were in place, were not used. Encryption is not consistently applied which make sharing electronic information difficult both internally and externally in Councils and with other agencies and organisations.

Technologies used by different agencies and organisations are not compatible, which makes information sharing difficult. With satisfactory information security and information governance arrangements in place electronic sharing of information on compatible systems can be fast and efficient. Systems need to be in place to ensure that electronic systems which are used nationally, have good information governance arrangements in place. An example where these arrangements are problematic is the electronic national Careworks database which is used in the Youth Offending Teams. However, as information cannot be deleted off Careworks this makes compliance in relation to the retention and deletion of records problematic.

The process should drive the technology not the process being driven by the capability of the technology.

6.3 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?

6.4 Yes, the law should mandate specific technical safeguards and standards including encryption on electronic systems including portable devices.

6.5 Question 22

How, in your view, could 'privacy enhancing techniques', such as the anonymisation of 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?

6.6 See also the answer to Question 4 above. It would be helpful to have further national guidance for agencies and organisations produced on the deployment of 'privacy enhancing techniques' as there is presently very little guidance available on this.

7.0 Section 6: International comparisons

7.1 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.

7.2 No comments.

7.3 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?

7.4 No comments.

7.5 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?

7.6 No comments.

7.7 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.

7.8 No comments.

8.0 Section 7: Additional questions

8.1 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?

8.2 It would be helpful to have more robust monitoring processes of electronic systems to ensure good standards of security and information sharing protocols to ensure good standards for information sharing. It was helpful to specify that agencies/organisations undertaking CRB checks should only share information with agencies/organisations who also undertake CRB checks in the recent guidance on information sharing produced by the Information Commissioner.

8.3 Question 28

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

8.4 No comments.