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By email: contact@datasharingreview.gsi.gov.uk

15 February 2008 [extension until 22 Feb granted]

Dear Mr Thomas and Dr Walport

Re. Use and Sharing of personal information in the public and private sectors consultation

The Human Genetics Commission (HGC) is grateful for the opportunity to respond to your consultation on the use and sharing of personal information which we believe is both timely and important. The HGC is the Government's advisory body on developments in human genetics and their ethical, legal, social and economic implications and it has a UK-wide remit. As Chair of the HGC's Databases Monitoring Group, I have been asked to respond on behalf of my fellow Commissioners. Our response relates specifically to issues raised by the sharing of personal genetic information, in line with our remit.

My colleagues and I would be extremely grateful if you would keep us informed of progress of your review. I am happy for you to reproduce this response and to quote from it in your final report. To comply with the HGC's open working style a copy of this response will be placed on the HGC's website.

Yours sincerely,

Human Genetics Commission

Section 1: Background

Question 1. Please explain what your interest in information sharing is

Comments: The HGC is the UK Government's advisory body on new developments in human genetics and how they impact on individual lives. It has an interest in the use of genetic information and the implications this has for individuals and society. In 2002, the Commission published a report 'Inside Information' which outlined key principles in balancing interests in the use of personal genetic data. The Commission has continued to monitor developments in the collection and use of genetic information since this publication. In responding to this consultation our focus will be specifically on the use and sharing of genetic information (including when linked to other personal information).

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: In relation to genetic information, the sharing of such information would be in accord with one of the principles set out in 'Inside Information' namely genetic solidarity and altruism. The benefits of, for example, research involving genetic information (supplied or derived from biological samples with informed consent) is likely to be of benefit to society, rather than to the immediate benefit of individuals providing such information, through the increased knowledge it will bring about disease and possible medical interventions. Benefits to individuals of sharing their genetic information are likely only to be within a clinical context, for example, between health care professionals, with the consent of the patient, in order to ensure most appropriate treatment. The development of pharmogenetics is likely to mean such data sharing may become more important. The sharing of genetic information about individuals, possibly via a network of healthcare professionals, may also bring benefits to blood relatives (for example, to identify otherwise unsuspected genetic risk or to inform their reproductive decisions).

Question 3. What in your view are the key risks of sharing personal information to a) individuals and b) society? Please provide examples.

Comments: The key risks of sharing genetic information are similar to those regarding all personal information – the risks of breaches of a duty of confidentiality, improper use of the information, potentially leading to unfair or discriminatory treatment of individuals or groups, etc. However, there are some additional risks pertaining to genetic information in that sharing such information may bring harm to that individual but also biological relatives. The information is rarely individual and can lead, for example, to stigmatisation. Where the information is shared in an uncontrolled manner, relatives may be suddenly confronted with a set of decisions for which they may be unprepared or which may impact significantly on their plans or interests. The societal implications of sharing information relate more broadly to the wider social and political context and the presence or absence of robust governance. The increased potential for sharing of information (due to improved technology and also increased availability of such information) may result in its unjustified use for purposes beyond the original aim of collecting such information. This in turn risks

undermining the willingness of individuals to provide information which could be used for benefit of all, or to provide true and complete information.

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: There are many opportunities, for example, population based and familial medical research leading to the understanding of complex disease, identification of new disease mutations and understanding of inheritance leading to new treatments and better counselling.

The scope and methods of sharing genetic information that pose greatest risk include the possibility of public access to others' genetic information (even if anonymised) and the opportunity this could provide for 'lay' diagnosis if an individual had access to their own genome sequence. Thus the technological advances alongside public access bring both great opportunities as well as risks. Other risks relating to sharing genetic information include the potential for interference with personal relationships and family life (eg through familial searching within the NDNAD or deduction of non-paternity). Other limitations with the possible sharing of genetic information in relation to patient records include expertise in interpreting such data amongst different health care professionals. The main risks are in the context in which the information is provided, in particular where information with important health implications (e.g. predictive of disease) or personal implications (e.g. non-paternity) is provided in an uncontrolled way and without adequate counselling and information.

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: The HGC is currently considering the scope and use of information on the Home Office National DNA Database with a view to advising Government. Questions which the HGC will address include whether the scope and range of samples and profiles currently held on the database is appropriate and justified in relation to the purpose for which the database was established and its effectiveness in meeting its objectives. At present we are undertaking a "Citizens' Inquiry" into the forensic use of genetic information, which will collect evidence from a wide range of sources in order to enable participants to identify, examine and discuss the key social and ethical issues involved. The inquiry will report in the Spring of 2008 and the findings will be published independently and contribute to a broader HGC report on the forensic use of genetic information, planned for later in the year. Both the inquiry report and HGC report are likely to contain findings and recommendations that are strongly relevant to your review and I should be happy to provide you with a copy of these as they become available.

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: Please see comments in relation to question 5, as the National DNA Database comprises large amounts of data generated and held by companies in the private sector, which provide DNA profiling services.

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: The Human Tissue Act prevents the sharing of genetic information without the consent of the sample donor. There may be cases where sharing genetic information in circumstances where consent cannot be gained, if for example the sample donor has died or contact is otherwise lost, would be beneficial to blood relatives. While sharing of patient records within the NHS is desirable, this should be balanced against privacy issues.

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: There is a fear amongst some that the insurance industry use data about an applicant's genetic status gathered to investigate medical conditions, in respect of applications for insurance cover. There may be the possibility of this happening unofficially or inadvertently in some cases. Account should be taken of public perceptions as to the trustworthiness or otherwise of Insurers and similar concerns have been raised in relation to employers.

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: There may need to be further powers relating to implementation of guidelines and inspection especially as data are being held for as yet unspecified future use (eg by the large genetic epidemiological studies such as UK Biobank). The Commission has identified a need to reconsider whether there is a case for creating additional penalties for improper use of information in order to discourage such misuse and to reassure those providing information – especially genetic information – for the benefit of others, for example in projects of biomedical research.

Question 10. In your view, how well do public authorities and private organisations adhere to the second principle of the DPA? [i.e. 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] How valuable do you believe the second principle is? Please provide examples and the reasoning behind your response.

Comments: The second principle is very valuable as it acts as a constraint on use of personal information. Such constraint may become even more important as large-scale databases, including those with genetic information, are built up. The fact that information is held should not propel inappropriate or

unnecessary access or sharing. (Also, see the comments in response to question 17).

Question 11. What technical, institutional or societal barriers stand in the way of the effectiveness of the DPA? Please provide examples.

Comments: No comment

Question 12. What further powers, safeguards, sanctions or provisions do you believe should be included in the DPA.

Comments: Greater powers of inspection to ensure that data are not being shared without consent or in an unjustifiable way. We would also wish consideration to be given to case for additional penalties for improper sharing or use of sensitive personal information, including genetic information.

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: No comment

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: No comment

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: No comment

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: The consent requirements in relation to the taking of DNA samples for paternity testing may not be understood in every case. Also the rights of those providing voluntary DNA elimination samples to the police, and the possible consequences of doing so, may sometimes not be fully explained. The issues surrounding volunteer consent are currently being addressed by the NDNAD Ethics Group. (Also see the comments in response to question 17.)

Question 17. What, if any, barriers would a requirement for gaining consent create to the sharing of personal information? Please explain your reasoning.

Comments: The use of routinely collected health information for epidemiological research is one example where informed consent may create a barrier. Some forms of public health research could be made unviable if consent were to be insisted on. Other methods could be developed to provide a warrant or mandate for

such research – for example more public engagement around data sharing for such research purposes, community consent, transparent governance arrangements. In relation to large scale genetic databases, the difficulties relate to open consent for future use and perhaps also the difficulties of truly informed consent about the nature of potential data linkage. Concerns also relate to situations in which the data subject is, or becomes, deceased or mentally incapacitated.

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: Certainly, as above, organisations should explain their use and sharing of personal information to the public using the full range of public engagement techniques that are well developed in other fields.

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](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)?

Comments: We consider public involvement to be vital in the development of such policy.

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: There are both positive and negative impacts to consider. Technological advances make data sharing easier and therefore unauthorised sharing may be more likely to occur. However, sophisticated encryption methods also make data more secure. Technology can make the detection of unauthorised access easier to trace because it can be monitored through an electronic footprint left behind.

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: While the HGC does not have a decisive position, exploration of this issue among relevant stakeholders would be useful.

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:	For the purposes of biomedical research, where irreversible anonymisation or pseudonymisation is possible (insofar as it is realistically possible with genetic information) without compromising the quality of the results, we would suggest that encouragement might be given to these methodologies (i.e. making the information no longer 'personal' information) as an alternative to sharing personal information in these particular contexts.

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:	no comment

	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:	no comment

	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:	We believe that in Denmark, information relevant to medical treatment of family members can be shared without consent.

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: No comment

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: We would emphasise our concerns about linking databases of genetic information, the potential for deductive identification and the consequences for individuals and their families.

Question 28. Please set out any additional suggestions or observations you have that you believe will be of assistance to the review.

Comments: In *Inside Information*, HGC took some trouble to define what is meant by personal genetic information. Reading 'personal information' here consistently with the DPA 1998 (as information that relates to a living individual who can be identified from that information or deductively from that information and other available information) we would note that genetic information about a deceased individual can have implications for living or future blood relations which should be taken into account (this applies to forensic use of information as much as to use in a healthcare setting).