RESPONSE TO

CALL FOR EVIDENCE ON THE CURRENT DATA

PROTECTION LEGISLATIVE FRAMEWORK

Introduction

AvMA's role is to support and advance the interests of patients who have been injured as a result of receiving medical treatment. It operates a Referral Panel to which solicitors with specialist expertise in pursuing clinical negligence claims on behalf of claimants belong, subject to passing stringent qualification tests. It runs high quality specialist training for those working in the field of clinical negligence claims. We also operate a helpline, Monday to Friday, which allows us to give advice us potential claimants and complainants. We also gather statistics from our helpline to gauge the impact on access to justice of changes in the law and gauge the need in the population for legal advice as to claims. One particular area where we have expertise is in advising clients on making a complaint using the NHS complaints procedure (or similar for private health providers). As part of this work we advise clients on their rights under the Data Protection Act to obtain copies of their medical records. We also have a database of expert witnesses, access to which is available to our solicitor and barrister members.

We therefore make the following comment on the Data Protection Act 1998 in respect of the issues that are relevant to the aims of AvMA and the interest of our clients.

Ministry of JUSTICE

Call for Evidence on the Current Data Protection Legislative Framework

List of questions for response

We would welcome responses to the following questions set out in this consultation paper. Please email your completed form to: informationrights@justice.gsi.gov.uk or fax to: 020 3334 2245. Thank you.

General

Question 1. **What are your views on the current Data Protection Act and the European Directive upon which it is based? Do you think they provide sufficient protection in the processing of personal data? Do you have evidence to support your views?**
Comments: As a charity that campaigns for patient safety and justice, our replies are confined only to issues relating to the disclosure of health related data. The wide definition of data contained in the DPA provides access to all and individual patients' data. Previously problems were encountered in obtaining documents where for instance the patient's treatment was the subject of an independent inquiry. Some difficulties continue if a healthcare provider does not give full disclosure but the remedies contained in the DPA are adequate.

Definitions

Question 2. **What are your views of the definition of "personal data", as set out in the Directive and the DPA?**
Comments: It is often simple to identify individual subjects of anonymised studies. Therefore in the context of healthcare provision consideration should be given to include such subjects within the scope of the DPA. We as an organisation have on occasion received confusing and conflicting advice when we have sought advice from the information commission. We believe clearer procedures and more training may prevent this occurring in the future

Question 3. **What evidence can you provide to suggest that this definition should be made broader or narrower?**
Comments: In small studies with a healthcare perspective, individuals are easily identified from personal characteristics or unique aspects of care or condition.

Question 4. **What are your experiences in determining whether particular information falls within this definition?**
Comments: Not applicable.

Question 5. **What evidence can you provide about whether biometric personal data should be included within the definition of "sensitive personal data"?**
Comments: Not applicable.

Question 6. **If as a data controller you process biometric data, do you process it in line with Schedule 3 of the DPA which imposes an additional set of conditions?**
Comments: Not applicable.

Question 7. **Are there any other types of personal data that should be included? If so, please provide your reasons why they should be classed as "sensitive personal data"?**
Comments: Not within our area of interest.

Question 8. **Do you have any evidence to suggest that the definitions of "data controller" and "data processor" as set out in the DPA and the Directive have led to confusion or misunderstandings over responsibilities?**
Comments: No.

Question 9. **Do you have any evidence to suggest that the separation of roles has assisted in establishing responsibilities amongst parties handling personal data?**

Comments: Not applicable.

Question 10. **Is there evidence that an alternative approach to these roles and responsibilities would be beneficial?**
Comments: No.

Question 11. **Do you have evidence that demonstrates that these definitions are helpful?**
Comments: It is helpful to a patient to know who the data controller is and to whom to direct his request for data. In the event of a dispute or a complaint to the data commissioner the patient is assisted by their clarity in relation to roles and to control of information.

Data Subjects' Rights

Question 12. **Can you provide evidence to suggest that organisations are or are not complying with their subject access request obligations?**
Comments: Not consistently. From time to time our members/clients experience delays or partial disclosure.

Question 13. **Do businesses have any evidence to suggest that this obligation is too burdensome?**
Comments: While our member solicitors have reported complaints from general practitioners in particular we do not believe they are justified. With the increased use of data being held electronically providing copies becomes quicker and less costly.

Question 14. **Approximately how much does it cost your organisation to comply with these requests?**
Comments: Not applicable.

Question 15. **Have you experienced a particularly high number of vexatious or repetitive requests? If so, how have you dealt with this?**

Comments: Not applicable.

Question 16. **What evidence is there that technology has assisted in complying with subject access requests within the time limit?**
Comments: Computer held medical records and radiology makes copying quicker and cheaper for the healthcare provider. It also provides clearer copies for the patient.

Question 17. **Has this reduced the number of employees required and/or time taken to deal with this area of work?**
Comments: Not applicable.

Question 18. **Is there evidence to suggest that the practice of charging fees for subject access requests should be abolished?**
Comments: If a subject is in receipt of certain means tested benefits (such as income support) no fee should be paid at all. Otherwise fees should remain at their present level. While medical records can be voluminous increasing use of online data storage has made the process quicker and cheaper, however there is still a cost to the data controller.

Question 19. **Do you have evidence that the £10 fee should be raised or lowered? If so, at what level should this be set?**
Comments: Subject to our comment at Q18 regarding those in receipt of benefits the fee should be left as it is.

Question 20. **Do you have evidence to support the case for a "sliding scale" approach to subject access request fees?**
Comments: A flat rate charge is simpler to administer and easier for subjects to understand.

Question 21. **Is there evidence to suggest that the rights set out in Part Two of the DPA are used extensively, or under-used?**

Comments: Patients are most likely to use S13 and S14 of the DPA but the cost of litigation is prohibitive unless seen as part of a larger clinical negligence claim.

Question 22. **Is there evidence to suggest that these rights need to be strengthened?**
Comments: Patients would welcome the strengthening of the right provided for in S14. Of particular benefit would be if the Information Commissioner were able to investigate claims under S13 and S14 and order compensation/rectification rather than the subject having to have recourse to litigation.

Obligations of data controllers

Question 23. **Is there any evidence to support a requirement to notify all or some data breaches to data subjects?**
Comments: Yes the patient should have a legal right to be informed about any breach that has an affect on their health and healthcare provision.

Question 24. **What would the additional costs involved be?**
Comments: This question is for the Data Controller to respond to.

Question 25. **Is there any evidence to suggest that data controllers are routinely notifying data subjects where there has been a breach of security?**
Comments: No.

Question 26. **Do you have evidence to suggest that other forms of processing should also be exempt from notification to the ICO?**
Comments: Not applicable.

Question 27. **Do these current exemptions to notification strike the right balance between reducing burdens and transparent processing?**
Comments: Not applicable.

Powers and penalties of the Information Commissioner

Question 28. **What evidence do you have to suggest the Information Commissioner's powers are adequate to enable him to carry out his duties?**
Comments: None.

Question 29. **What, if any, further powers do you think the Information Commissioner should have to improve compliance?**
Comments: See our response to Question 22 above.

Question 30. **Have you had any experience to suggest that the Information Commissioner could have used additional powers to deal with a particular case?**
Comments: No.

The Principles-based Approach

Question 31. **Do you have evidence to suggest the current principles-based approach is the right one?**
Comments: No.

Question 32. **Do you have evidence to suggest that the consent condition is not adequate?**
Comments: No.

Question 33. **Should the definition of consent be limited to that in the EU Data Protection Directive i.e. freely given specific and informed?**
Comments: Yes.

Question 34. **How do you, as a data controller, approach consent?**
Comments: All clients who approach AvMA are informed that the information they are giving is being recorded in writing.

Question 35. **Do you have evidence to suggest that data subjects do or do not read fair processing notices?**
Comments: No.

Exemptions under the DPA

Question 36. **Do you have evidence to suggest that the exemptions are fair and working adequately?**
Comments: We comment in relation to health related records only. We believe the need for recording details of a person's health and medical treatment to ensure good communication between doctors and appropriate and consistent care requires an exemption which appears to be fair and working adequately.

Question 37. **Do you have evidence to suggest that the exemptions are not sufficient and need to be amended or improved?**
Comments: No.

International Transfers

Question 38. **What is your experience of using model contract clauses with third countries?**
Comments: None.

Question 39. **Do you have evidence to suggest that the current arrangements for transferring data internationally are effective or ineffective?**
Comments: Not applicable.

About you

Please use this section to tell us about yourself

Full name	Catherine Hopkins
Job title or capacity in which you are responding to this consultation exercise (e.g. member of the public etc.)	Legal Director of AvMA
Date	27th September 2010
Company name/organisation (if applicable):	AvMA
Address	44 High Street
	Croydon
Postcode	CR0 1YB
If you would like us to acknowledge receipt of your response, please tick this box	☐ (please tick box)
Address to which the acknowledgement should be sent, if different from above	

If you are a representative of a group, please tell us the name of the group and give a summary of the people or organisations that you represent.

AvMA

Please see title page