

## **Consultation on Charter of Patient Rights and Responsibilities**

The Information Commissioner's Office (ICO) welcomes the opportunity to respond to the above consultation as Regulator for the Data Protection Act 1998 (the DPA).

The ICO followed the passage of The Patient Rights (Scotland) Act 2011 with interest and is pleased to have influenced the content at the earliest stages. As the Charter of Patient Rights and Responsibilities (the Charter) states, although the 2011 Act introduced new rights for patients many exist already, such as those established via the DPA. In this regard, the ICO welcomes the articulation of many of the DPA rights in the context of health care.

The ICO notes the emphasis given to "Communication and Participation" within the document. Whilst this is largely made within the context of understanding health care options, the good communication practices outlined will assist in complying with Principle 1 of the DPA which requires that processing of personal data should be fair. Moreover, where consent is the basis of such processing, it must be informed consent and, where a patient exercises their Data Subject Access requests under s7 of the DPA, all information disclosed must be intelligible to them. The support mechanisms outlined in this section are therefore welcomed.

The ICO also welcomes the prominence given to security and confidentiality within the document, and trusts that this will further promote their fundamental importance given the sensitivity of personal information within health care. In addition, the issue of lawful disclosure is one on which the ICO is often asked for advice and it is particularly welcome that the Charter seeks to manage expectations by providing illustrations when non-consented disclosure complies with the DPA. However, it may be helpful to indicate that such examples are not exhaustive.

Finding the balance between rights awareness and managing expectations is especially important in exercising subject access rights. While the individual's right to request a copy of the health record is absolute, the right to receive is qualified and often the ICO is asked to adjudicate on complaints that some of the record has been withheld or redacted. Although the excellent information leaflets produced by HRIS cover this, the ICO believes that at least a passing reference in the Charter to the qualified nature of the right to access would provide a better balance and assist in managing expectations.

The matter of accuracy is dealt with in the Safety section in terms of an individual's responsibilities to assist in keeping their health records correct and up to date. While it is acknowledged that individuals have to accept some responsibility towards this by providing accurate information in a timely fashion, it is a shared responsibility in that health care professionals need to ensure that information entered by them is correct. The ICO welcomes, therefore, the inclusion of this right in this section but believes the current wording could raise false expectations regarding an individual's ability to have perceived inaccuracies corrected. The DPA right to accuracy pertains to matters of fact and not matters of professional opinion. This is a recurring enquiry to the ICO by individuals seeking to have an opinion removed from their record when this is unlikely to happen. The expectation of accuracy must, therefore, be managed from this perspective and some mention could be made in the Charter to this qualification.

In Part 3, the ICO welcomes recognition in terms of being an independent source of information or advice. However, the sentence preceding the contact details could be somewhat misleading as the ICO's role is to provide advice and guidance about privacy rights and has no locus in determining how personal health information is used and protected. This is for the data controller to determine but if someone believes their personal information has not been used or protected in compliance with the DPA, the ICO is able to provide advice and guidance as to how this might be addressed. It is therefore suggested that the preceding sentence to the contact details is replaced with: *For more information about your rights under the Data Protection Act, contact:*

ENC – Respondent Information Form