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Senior Assistant clerk
Committee for Health, Social Services and Public Safety
Room B32
Parliament Buildings
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28 August 2015

Dear Ms Austin

The Health and Social Care (Control of Data Processing) Bill

We thank you for the opportunity to provide further views on the Health and Social Care (Control of Data Processing) Bill to the Health Committee. In our preliminary response of 31 July we commented on some overarching aspects of the Bill. In it, we welcomed the policy intentions of this draft legislation, as we agreed that having a statutory basis for allowing the disclosure of information for the purposes of improving health and social care will underpin the processing.

We note that clause 1 of the Bill gives the DHSSPS (the Department) the power to make regulations in connection with requiring or regulating the processing of information for medical or social care purposes in the interests of 'improving health and social care' or 'in the public interest'. Furthermore clause 2 of the Bill provides the Department with the power to make regulations establishing a new committee to authorise the processing of confidential information. We welcome the safeguard contained within clause 1(8) of the Bill that regulations made under this section must not be inconsistent with any provision made by or under the Data Protection Act 1998 (the DPA). We would hope to work closely with the Department to ensure that any such regulations under this Bill are compliant with the DPA.

We also welcome the provision for the Department to prepare and publish a Code of Practice on the processing information, which Health and Social Care bodies will be obliged to follow. Again, we would be keen to work with the Department on the development of this Code to ensure that Health and Social Care bodies are following best practice in relation to making disclosures in compliance with the DPA.

As we highlighted in our previous correspondence, there are some aspects of the Bill which we feel requires further consideration and clarification in terms of compliance with the data protection principles. A fundamental component of the first data protection principle is that personal data should be processed 'fairly'. To comply with this principle, the DPA requires that individuals are normally informed of the purposes for which their data will be used. This requirement is strongest where the data being processed is sensitive in nature, such as information relating to an individual's health.

As we have previously acknowledged, the Bill will provide a legal gateway for the Department to allow the disclosure of health and social care data in certain circumstances. This may provide an exemption for organisations from the non-disclosure provisions as per section 35 of the DPA. In this case, the data controller will be exempt from compliance with the first principle except to the extent to which it requires compliance with the conditions in Schedules 2 and 3 and only to the extent that the exemption *would be inconsistent* with the disclosure in question. The view of this office would be that given the scale and nature of what is being proposed, providing fair processing information would not be inconsistent and this exemption is unlikely to take effect. Consequently, we would emphasise that engaging with the general public on the secondary use of their health and social care data is essential. Any use of personal data can lead to a high degree of concern with the general public, albeit there is a clear ethical reason for the processing. Previous experience indicates that using people's information in a way that they expect and understand can help build public confidence in both the secondary use of their information and the service being delivered.

In our previous response we had noted some concerns with regard to certain terms within the Bill which may need to be more strictly defined. For example, Clause 1(10)(b) defines social care information to include information which relates to the 'social well-being' of an individual. Whilst we appreciate that social care information is perhaps more difficult to define than health care data, information relating to 'social well-being' has the potential to be interpreted much more widely. We would therefore recommend that further consideration is given to this. Furthermore, we note that the Bill will require or authorise the processing of information where it is necessary or expedient 'in the interests of improving health and social care' or 'in the public interest'. Whilst we appreciate that the Department cannot anticipate every situation that is likely to arise, consideration should be given to what kind of circumstances that might be covered by public interest, but not 'in the interests of improving health and social care'.

We understand that the Department has previously explained in the consultation response document that the Bill will allow for the sharing of information and will not have the power to require it to be shared. However, clause 1(2)(a) of the Bill says that regulations may make provision for '*requiring* or authorising' the disclosure, to a relevant person involved with improving the physical or mental health of people in Northern Ireland, or, with the prevention diagnosis or treatment of illness. This would suggest that there may be occasions when data will not only be authorised to be disclosed, but will be required to be. In these cases, it is imperative that the Department is open and transparent with the public as to when processing may take place. We would welcome clarification as to whether there is an opt-on mechanism in place in this framework.

We trust that the concerns that we have raised are helpful to the Committee and we look forward to engaging further with the Department in the development of the regulations and Code of Practice to ensure that they fully comply with the requirements of the DPA.

Yours sincerely



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31 July 2015

Dear Ms Austin

Health and Social Care (Control of Data Processing) Bill

Thank you for your correspondence seeking our views on the Health and Social Care (Control of Data Processing) Bill that was introduced into the Assembly on 16 June 2015. The Information Commissioner's Office (the ICO) is the UK's independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals. As such, we have a vested interest in ensuring that this Bill complies with the requirements of the Data Protection Act 1998 (the DPA).

By way of providing context, this office previously responded to a consultation from the DHSSPS (the Department) on the proposal to introduce primary legislation for the use of health and social care service user identifiable information for secondary purposes in controlled circumstances. Whilst we generally welcomed this proposal, we outlined some concerns relating to compliance with the first data protection principle, i.e., that information is processed fairly and lawfully and that certain 'conditions' are met. In the case of sensitive personal data (information relating to the physical/mental health of an individual), a data controller must be able to satisfy a condition from Schedule 2, and a further condition from Schedule 3.

The Bill in question seeks to introduce a legal basis to allow for the processing of health and social care data without the consent of an individual where it is necessary in the interests of improving health and social care, or, where it is in the public interest. As such, it would appear that such processing would satisfy the conditions for processing set out in Schedule 2 para 5(b) and Schedule 3, para 7(b).

Whilst we appreciate that the proposals will provide a legal gateway for the Department to allow the disclosure of health and social care data in certain circumstances, thus satisfying a relevant condition for processing, the processing may still may not be compliant with the first principle if the processing is fundamentally unfair to individuals.

As it stands, we have some concerns regarding the fairness of the provisions of this Bill on the rights and freedoms of individuals. Where individuals' rights are unreasonably overridden the processing, even though it may satisfy a Schedule 3 condition, may nonetheless be unfair. We are aware that the Department has engaged in external consultation on the proposal to use patient data for secondary uses, however it might be worthwhile to engage with the general public and consider their views on the re-use of their data for secondary purposes.

We understand that in the consultation document report to 'Caring for you and your information' (November 2014), the Department acknowledged that there was a concern amongst some respondents that an individual should have the right to 'opt-out' of secondary uses. In response, the Department explained that the proposals will establish a statutory basis which will *allow* for the sharing of information, and will *not* have the power to require it to be shared. However, in Section 1 (2)(a) of the Health and Social Care (Control of Data Processing) Bill, regulations may make provision for '*requiring* or authorising' the disclosure, to a relevant person involved with improving the physical or mental health of people in Northern Ireland, or, with the prevention, diagnosis or treatment of illness. This would suggest that in cases where the personal data may assist with either of these provisions that the data controller would be required to share the data.

In addition to this, there are specific elements of the Bill which we will need to consider in greater detail, such as whether the disclosure of data for secondary uses is compliant with the second data protection principle. The second principle provides that personal data is to be obtained only for one or more specified purposes and shall not be further processed in any manner incompatible with that purpose. If an individual provides information about their health condition or social well-being to an organisation with the belief that it will only be used in relation to their own direct treatment/care, and that information is then processed further for secondary purposes, then it may be arguable that this is not compatible with the second principle.

Furthermore, the Bill contains terms which have the potential to be interpreted quite broadly, such as the provision in section 1 (1)(b) which allows for the

processing of personal data for medical or social care purposes where it is in the 'public interest'. Whilst we understand that 'public interest' can be a difficult term to define, it would be useful for the Department to provide greater clarity i.e. what level of public interest is required and what kinds of cases this will apply to.

As you will be aware from a separate communication, we wish to provide the Committee with further detail about these concerns. Unfortunately, because of resource implications at the present time, it is unlikely that we will be able to provide a fuller response until the week commencing 17th August. We apologise for any inconvenience caused by this, but given the potential impact of the Bill, we are sure you will appreciate that this is necessary.

Yours sincerely



Dr Ken Macdonald
Assistant Commissioner for Scotland & Northern Ireland