Information Commissioner's Office

Upholding information rights

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ICO Response – The Mental Capacity Bill (NI)

The Information Commissioner's Office (ICO) is pleased to further respond on the Mental Capacity Bill (the Bill) for Northern Ireland introduced into the Assembly on 8 June 2015. We wish to establish from the outset that due to the response turnaround time we have not been able to consider all aspects of the Bill in detail. However, we have provided some comments below, which we hope will be helpful. The ICO is the UK's independent public authority set up to uphold information rights. We do this by promoting good practice, ruling on concerns, providing information to individuals and organisations and taking appropriate action where the law is broken. The ICO enforces and oversees the Freedom of Information Act 2000, the Environmental Information Regulations 2004, the Data Protection Act 1998 and the Privacy and Electronic Communication Regulations 2003.

The main focus of interest for the ICO in the Bill is compliance with the Data Protection Act 1998 (DPA) and our response will focus on the aspects and areas we feel are relevant in relation to this.

Part 1 Principles

As previously outlined we can appreciate the significance of the Bill and overall, it should be noted that the proposed principles based approach with regard to the common law presumption of capacity, whereby a person is assumed to have capacity unless it is established otherwise, must take due regard of the principles of the DPA. The Bill highlights the fact that people may lack capacity to make decisions for many reasons. This aspect, as well as taking into account the outlined Lasting Powers of Attorney indicates the importance which needs to be given to the fair and lawful processing of what is likely to be sensitive personal data on behalf of individuals.

Part 2 Lack of Capacity

We note that the Bill defines the term "lacks capacity" in a way that makes it clear that it is not a blanket assessment and also acknowledge the underpinning principle of the Bill that just because a person lacks capacity in relation to a particular matter, this does not mean that the person lacks capacity in relation to all matters affecting them at that time or in the future. Therefore the test in reaching a decision based on capacity relating to the exact 'issue' and the 'specific time' of the issue should also take into context the ability to consent or otherwise by the individual with regard to the processing of personal or sensitive personal data.

The DPA requires that conditions for processing need to be in place when processing personal and sensitive personal data. When we responded previously to the draft NI Mental Capacity Bill we commented on how the intrinsic concept of implied capacity needs to take into account these conditions (in particular) whereby consent or, in the case of sensitive personal data, explicit consent may be the condition being relied upon.

The proposed principles based approach with respect to the common law presumption of capacity, whereby a person is assumed to have capacity unless it is established otherwise, is of particular importance in this regard. This needs to take into consideration whether the individual does indeed have the capacity to give consent or explicit consent. For the processing of any personal data under the DPA it must be considered what is *fair* to the individual. Principle 1 of the DPA requires that personal data must be processed fairly and lawfully and therefore this concept of fairness needs considered in light of the Bill. Fair processing to ensure protection of privacy to individuals as well as understanding of how this will work in practice needs to be given careful consideration. We

suggest this may be an element to review to consider for incorporation into any relevant code of practice issued under s276. The ICO would be pleased to work with the Department with respect to any relevant code of practice to ensure that data protection requirements are properly considered.

In addition the processing must also be lawful. We would emphasise that in order for the processing of (sensitive) personal data to be lawful certain 'conditions' must be met. In these cases, it is likely to be sensitive personal data that is being processed, and so a condition from both Schedule 2 and 3 of the DPA is required to be satisfied. Note that Schedule 3 is supplemented by additional conditions contained within The Data Protection (Processing of Sensitive Personal Data) Order 2000. The Bill will allow schedule conditions to be met when personal information is being processed for the purposes identified within it. Where capacity exists this should be through consent/explicit consent, whereas in other circumstances this will be through the legal powers granted, as detailed in the Bill.

Data Sharing

The DPA does not prevent the sharing of information as long as the sharing is compliant within the 8 Principles of the DPA. The Bill includes many layers of sharing of information as highlighted in the specific provision of information clauses. Part 11 covers the transfer of information of individuals between different jurisdictions. We would anticipate this type of activity would require sharing across several agencies or organisations. Due regard should then be given to this to be compliant within the DPA and we would strongly recommend that privacy impact assessments should be undertaken on the processes being adopted for any aspect of information sharing. Again we suggest that how this works in practice may need to be explicitly outlined within the relevant codes of practice.

Data sharing needs to take account of whether there is a legal obligation to share information, which this legislation will provide in many cases. In addition the DPA requires that information should be relevant, adequate and not excessive, therefore only the information that is absolutely necessary should be shared or disclosed.

In addition, it is foreseeable that personal information relating to an individual will be shared across a range of agencies for the purposes of that individual’s care and treatment. In this event, agencies should ensure that any data sharing is compliant with the 8 Principles, and this is also given due regard within any

Codes of Practice arising out of this Bill, including a requirement to have in place data sharing agreements.

Fair processing

We welcome the clauses pertaining to the 'provision of information' as part of the fair processing aspects of the Bill. One of the key principles of the DPA is the requirement for organisations to be fair to individuals by providing them with adequate fair processing information, telling the individual why they are using their information and what for. Clause 55 says that 'Regulations may make provision requiring a prescribed person to give prescribed information to a prescribed persons' in instances where an individual had been detained. We would recommend that the Regulations give this provision greater clarity, and explicitly state who the 'prescribed persons' are and what the 'prescribed information is'.

We highlight the fact that the term 'information' is used interchangeably and in a variety of contexts throughout the Bill. With regard to this clause, the term is used to describe the requirement to explain to an individual (or their representative) details of why they are being detained, and their rights in respect of this. In other contexts, 'information' is used in their personal sense, i.e. personal data as defined by the DPA.

Individual Rights

It will also be important to note that under the DPA, individuals have certain rights in respect of their personal data. In cases where an individual lacks capacity, these rights may be bestowed on the power of attorney where that power exists. One of the main rights an individual has is their right to access their own personal data, known as the 'right of subject access'. This includes access to their health records as defined under s68 (2) of the DPA.

For example, where consent has to be sought, the attorney would determine whether it was given, the attorney can exercise subject access rights and it would be the attorney who is given the fair processing information. So in cases such as this it would be the attorney who would have the power to make decisions on behalf of a person in situations where that person who does not have the capacity to do so for themselves. This Bill would then as it stands further strengthen this position and give a clear legal power to the attorney in these circumstances. In the case of lasting powers of attorney it will be important in these circumstances that the information about the individual remains their

personal data in terms of the DPA, albeit the legal representative is acting on the person's behalf.

Whilst the right of subject access is a strong right in law, it should also be noted, especially with regard to individuals who may lack capacity that The Data Protection (Subject Access Modification)(Health) Order 2000 contains an exemption from subject access if the disclosure of that data would be likely to cause serious harm to the physical or mental health condition of the data subject or any other person. Reference should be made to this within codes of practice.

Part 8 - Research

We note that Part 8 clause 130 - 135 provides a basis for intrusive research to be carried out on, or in relation to, a person who lacks capacity to consent to it. For the purposes of clause 130, research will be deemed 'intrusive' if it would be unlawful to carry out the research on a person who had capacity to consent to it, but did not give their consent. In order for the research project to be approved it must meet certain criteria: that the research must be connected with the condition/treatment of the individual; that there must be 'reasonable grounds' for believing that the project would not be as effective as confining the research to only those who have consented; and that there is a potential benefit to the individual.

We note in particular, that if the research will not be of benefit to the individual without imposing a burden on them but that it will provide knowledge on the condition/treatment for others, then there must be 'reasonable grounds' for believing that the risk to the individual is likely to be negligible, and it will not interfere with their privacy in a 'significant way' or be 'unduly invasive or restrictive'.

Furthermore, we note that clause 133 places a requirement on a person conducting research to take 'reasonable steps' to seek the advice or opinion of a person, who is engaged in caring for the individual or is interested in their welfare, as to whether the research should take place. In the event of a suitable person not being able to be identified, the researcher must appoint an independent person, with guidance from the Department, to be consulted. If it is this person's opinion that had the individual, had they possessed capacity, that they would not have been likely to consent to the research, the researcher must ensure that the project should not go ahead. It is important to note that if a lasting power of attorney is in place, then it is the attorney who must give consent.

Whilst we appreciate that this is a proposed safeguard to protect the privacy rights of the individual, it would appear that this may be a decision for the 'appropriate body' to make rather than the researcher, prior to approval of the project. Our overriding view is that although an individual may lack capacity, the individual still has the same right to privacy as an individual who does have the capacity to withdraw consent.

Full regard should be taken of any privacy risks to the individual and that these are mitigated. Further consideration should be had as to whether the research provision is necessary, and compliant with both the DPA and Human Rights Act 1998 (HRA). Given the nature of the Bill and the individuals whom the legislation may involve our view is that the Assembly must be assured that this is compliant with the HRA and note that the processing of any personal data, if it is not compliant with the HRA, would also mean failure to comply with the DPA. If the Assembly is fully satisfied that this provision is HRA compliant, detailed guidance around this specific provision should be provided in the Code of Practice, so that researchers can be confident they are conducting ethical research within the confines of the Bill.

Security

With regard to additional safeguards for serious interventions, the process relating to formal assessment of capacity and in particular a written 'statement of incapacity' is highlighted. The requirements relating to the security of personal data contained in this type of record and overall in relation to records management associated with the Bill needs careful consideration, again to comply with the requirements of the DPA. The ICO have taken action against organisations, including issuing civil monetary penalties, which can be up to £500,000 for serious breaches of data protection. We would remind organisations of the importance of ensuring good practice with regard to both data protection and good records managements and the powers of the ICO to take action if required.

Finally, the Bill highlights a number of organisations or parties who may be subject to the Freedom of Information Act 2000. These organisations must be aware of their requirements and responsibilities with regard to the legislation and take due account of the information that may be requested from them in relation to these matters. Aspects of this should be considered within the relevant PIA's

In conclusion we hope the issues we have highlighted are helpful. We would as detailed above welcome direct involvement in the relevant Codes of Practice with respect to this Bill as they are developed and we look forward to engagement with the Department in this respect in the coming months.

If you wish to discuss any aspect of this response with us, please do not hesitate to contact me in the Belfast office.

Yours sincerely

Dr Ken Macdonald
Assistant Commissioner for Scotland & Northern Ireland