

FROM THE MINISTER FOR HEALTH,
SOCIAL SERVICES AND PUBLIC SAFETY



Department of
**Health, Social Services
and Public Safety**

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Our Ref: AGY/341/2015

Date: // June 2015

Dear

I refer to the forthcoming meeting of the Committee on Wednesday 17 June in which Departmental officials are scheduled to give evidence on the principles of the forthcoming Health and Social Care (Control of Data Processing) Bill.

You will recall Departmental officials provided an update to the Health Committee on the 11 February on the outcome of the consultation exercise. The response to the consultation was overwhelmingly supportive of the proposed legislation.

Please find attached a briefing paper for members' consideration and a copy of the Bill and Explanatory and Financial Memorandum.

The officials attending will be:

- Sharon Gallagher – Director of Corporate Services;
- Chris Matthews – former Head of Information Management Branch

Yours sincerely

SIMON HAMILTON MLA

HEALTH AND SOCIAL CARE (CONTROL OF DATA PROCESSING BILL)

POLICY OBJECTIVE

1. The Bill will provide a clear statutory framework, and robust and stringent safeguards, which will enable the use of health and social care information which identifies individuals to be used for medical or social care purposes which are designed to benefit health and social care, or achieve some other tangible benefit that might reasonably be described as a public good, without the consent of the individuals whose information may be used.
2. The provisions of the Bill will only be utilised where it is impossible or impracticable to gain the consent of individuals, anonymised or pseudonymised information would not achieve the desired outcome and the committee established under the provisions authorises the processing.
3. The policy objective underlying this Bill is to minimise the legal challenge risk which the Department and the Health and Social Care sector could potentially face as a consequence of using service user information, which identifies individuals, for purposes other than the direct care of the individual.

BACKGROUND

4. Every individual in Northern Ireland will use the services of the Health and Social Care sector at some point in their lives. In presenting for care from their GP, hospital consultant or other health or social care professional these individuals will provide information about themselves, in confidence, to help with the identification and treatment of their health condition or social care need. The information is provided under the common law duty of confidence to help resolve the individual's difficulties and improve their health and/or social care. This is called "primary use". Any further use of this information beyond the direct care of the individual is called "secondary use".
5. The risk of not having robust provisions in place is that the benefits to be derived from secondary use are not realised or that service information could

be used or disclosed in an inappropriate manner. Inappropriate use would have implications for the service user whose information has been compromised, the health and social care sector organisations as the guardians with responsibility for safeguarding the information, as well as those who are using the information.

6. This Bill will enable regulations to be made that establish a process which will ensure that information is only shared in very limited circumstances which are proven to be for medical or social care purposes and which will benefit health and social care or achieve some other tangible benefit that might reasonably be described as a public good.
7. The process will be robust, open and transparent. It will impose conditions on the use of the information and include penalties for those who fail to comply with these. This will protect the service user, the holder of the information and the individual or organisation applying to use it by establishing a clear, unambiguous framework to govern the secondary use of information.

COMMON LAW DUTY OF CONFIDENTIALITY

8. Sharing information which identifies individual service users for purposes other than the provision of direct care could lead to a potential breach of confidentiality.
9. The common law duty of confidentiality is not codified; it is based on previous judgements in court. Whilst various interpretations of the common law may be possible it is widely accepted that, where information which identifies individual service users is provided and held in confidence, disclosure may only be justified in one of three ways:
 - the service user has given consent for their information to be used;
 - the balance of public and private interest favours public interest disclosure; or
 - a statutory basis exists which permits or requires disclosure.

10. Evidencing service user consent or a statutory basis under the common law is straightforward. Consent is obtained or there is a statutory basis under which the sharing can happen. Satisfying the public interest under the common law is considerably more complex. It is about assessing the benefits and risks of sharing the information and basing a decision on that analysis. Currently, when using service user identifiable information for secondary purposes, where it is impossible or impracticable to gain the consent of individuals and the use of anonymised or pseudonymised information would not achieve the desired outcome, there is a reliance on the public interest and an increased legal challenge risk.

11. This Bill will establish a statutory basis for sharing information where gaining individuals consent is impossible or impracticable and the use of anonymised or pseudonymised information would not achieve the desired outcome.

12. It will not set aside the Data Protection Act 1998 or the Human Rights Act 1998. Any secondary use of information must continue to comply with the requirements of these two pieces of legislation.

CONTINUING WITH THE CURRENT ARRANGEMENTS

13. The Department has considered the implications of continuing with the current secondary use sharing arrangements and whilst steps have been taken to reduce the risk of a loss of personal information, the provisions in the Bill provide for a much more robust process.

EXPLANATORY AND FINANCIAL MEMORANDUM

14. Committee members were provided with an “in confidence” copy of the Bill and Explanatory and Financial Memorandum (EFM) in April. The provisions of the Bill have not changed but the wording of the EFM has been refined to ensure the policy objective of the Bill is clearly stated.