



Law Centre (NI)

**LAW CENTRE (NI) SUBMISSION TO THE  
COMMITTEE FOR HEALTH, SOCIAL SERVICES AND PUBLIC  
SAFETY**

**HEALTH AND SOCIAL CARE  
(CONTROL OF DATA PROCESSING BILL)**

**JULY 2015**

## **INTRODUCTION**

### **About the Law Centre**

The Law Centre is a public interest law non-governmental organisation. We work to promote social justice and provide specialist legal services to advice organisations and disadvantaged individuals through our advice line and our casework services from our two regional offices in Northern Ireland. It provides a specialist legal service (advice, representation, training, information and policy comment) in a number of areas of law, including community care and mental health law as well as social security, immigration and employment. Law Centre services are provided to member agencies across Northern Ireland. The Law Centre works with vulnerable clients who are likely to be affected by the Bill, including people with dementia, people with a learning disability, people with significant mental health issues (including people subject to the Mental Health Order), and their carers.

### **Commentary**

#### **Clause 1.—1**

Clause 1(1) sets clear limits on the scope of the Bill: namely, that any requirements for processing information or regulation of information are for ‘medical or social care purposes’. This means that other purposes (even if valid in themselves) cannot find a route to lawful disclosure of confidential information through this Bill. The meanings of ‘medical purposes’ and ‘social care purposes’ are defined in clauses 1(13) and 1(14):

(13) In this section “medical purposes” means the purposes of any of—  
(a) preventative medicine, medical diagnosis, medical research, the provision of care and treatment and the management of health services, and  
(b) informing individuals about their physical or mental health or condition, the diagnosis of their condition or their care and treatment.

(14) In this section “social care purposes” means the purposes of any of—  
(a) assessment of social care needs, research into social care or social wellbeing, and the provision and management of social care services, and  
(b) informing individuals about their social care needs or the provision of social care services in relation to them.

These definitions further make clear the limited scope of the Bill. In our view, there is no possibility of this Bill legitimately being used to process confidential information outside of health and social care.

Clauses 1(1)(a) and 1(1)(b) require that such processing for ‘health and social care purposes’ must also be necessary or expedient ‘(a) in the interests of improving health and social care’

or ‘(b) in the public interest’. It is reasonable to assume that ‘improving health and social care’ is always in the public interest which perhaps makes clause 1(1)(a) somewhat redundant. However, naming this particular public interest in this way perhaps helpfully serves to underline the emphasis in the opening paragraph of the clause that the processing must serve a medical and social care purpose.

Clause 1(1)(b) is necessary and appropriate: without this condition, the Bill would permit processing which was not in the public interest—something clearly undesirable. It is important to note that this does not mean that **any** public interest might be used to legitimate the processing of health and social care information without consent. The public interest must be one which is served by processing for a ‘medical and social care purpose’. Many things which are in the public interest such as the prevention of crime, the interests of national security, or the economic well-being of the country are not ‘medical and social care purposes’. Such other public interests cannot serve to access confidential information lawfully through this Bill. The Bill does not go beyond health and social care purposes.

As the Explanatory and Financial Memorandum lays out in paragraph 11, there are in general only 3 ways of a disclosure of confidential information being lawful (there is also a public interest in non-disclosure in operation in 2.):

1. The service user has given consent for their information to be used;
2. The balance of public and private interest favours public interest disclosure; or
3. A statutory basis exists which permits or requires disclosure.

Clause 1(2)(c) of the Bill creates a fourth possibility: namely, where the Committee established by the Regulations authorises disclosure in keeping with the Regulations of the Bill. Clause 1(2)(c) makes possible a lawful processing of confidential information which is not possible on the basis of the three options above: ‘processing the information must be taken to be lawfully done despite any obligation of confidence owed by that person in respect of it’. The Law Centre is supportive of this as for health and social care there are significant public interests which cannot be securely and reasonably achieved using the above 3 options. There is a need for a flexible and responsive process which is independent of those of who would wish to process the confidential information and avoids the need to create an explicit statutory basis for every situation which arises. To date in Northern Ireland, essential health and social care processes have operated on the basis of a judgement that the public interest warrants the processing, but this judgement has been made by those who seek to process the information. The arrangements proposed in the Bill will provide greater protection for service user confidentiality through requiring independent scrutiny and authorisation of such uses. We also have concerns that leaving judgement about the sufficiency of the public interest basis for disclosure to individual health and social care staff (who wish to process the information) does not provide a sufficiently clear legal basis to fully meet the requirements of article 8 of the European Convention on Human Rights.

## Proposal for an ‘Opt out’ provision

One of the most important safeguards for the individual interests of service users is a right to opt out of any processing of their confidential health and social care information which the Committee has authorised. Experience in England and Wales shows that opt out tends to be a rare occurrence in practice, but such a right ensures proper respect for the decisions of individual service users. The existence of a right to opt out of such processing of their confidential information would also serve to maintain and build confidence amongst service users about the proposed arrangements in the Bill. In England and Wales, a right to opt out is one of the ‘Standard Conditions of Approval’ of the Confidentiality Advisory Group<sup>1</sup> which state that the approval of processing by the Committee requires that the applicant ensure that: ‘The wishes of patients who have withheld or withdrawn their consent are respected’.

The Law Centre believes that this does not provide adequate protection of individual rights and interests and nor is it sufficiently apparent to service users. The right to opt out of processing authorised by the Committee as proposed by the Bill should be part of primary legislation, not a policy of the Committee. We therefore propose the amendment below.

### Proposed amendment to Clause 1

Clause 1, page 2, line 2, at end insert—

“( ) Subsection (2)(c) does not apply for or in connection with the processing of prescribed information of a relevant person in circumstances where that person has expressly withheld or withdrawn their consent to such processing.”

The purpose of clauses 1(13)(b) and 1(14)(b) is not clear. These clauses define ‘medical purposes’ and ‘social care purposes’ respectively as including provision of information to individuals:

(13) In this section “medical purposes” means the purposes of any of—

...

(b) informing individuals about their physical or mental health or condition, the diagnosis of their condition or their care and treatment.

(14) In this section “social care purposes” means the purposes of any of—

...

(b) informing individuals about their social care needs or the provision of social care services in relation to them.

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<sup>1</sup> Information about the Confidentiality Advisory Group (which is similar to Committee being proposed by the Bill) can be found at <http://www.hra.nhs.uk/resources/confidentiality-advisory-group/>. The Standard Conditions of Approval’ can be found at <http://www.hra.nhs.uk/resources/confidentiality-advisory-group/confidentiality-advisory-group-cag-standard-conditions-of-support/>

It is not clear to us why a Bill which is essentially about facilitating the lawful secondary use of confidential information should include the possibility of ‘informing individuals’ with respect to their primary care. These clauses also appear to be in contradiction to the intent of clause 1(7):

Regulations under subsection (1) may not make provision for requiring the processing of confidential information of a relevant person who is a recipient of services referred to in subsection (11)(a) solely or principally for the purpose of determining the care and treatment to be given to particular individuals.

Clause 1(15) provides an open-ended definition of ‘processing’ which is unnecessary and somewhat concerning:

(15) In this Act “processing”, in relation to information, means the use, disclosure or obtaining of the information or the doing of such other things in relation to it as may be prescribed for the purposes of this definition.

To achieve the “medical or social care purposes” at which the Bill aims, it is difficult to see what information processing would legitimately be involved that was not “use, disclosure or obtaining”. What might the “such other things” be which are open to be prescribed? One of obvious concern would be “selling”. Service users are likely to be supportive of uses which are in the public interest such as improving health and social care and the efficiency and effectiveness of health and social care services generally. However, we think that there is not likely to be service user and public support for confidential health and social care information being sold to the benefit of private interests. This open-ended definition of “processing” should be closed.

**Proposed amendment**

Clause 1, page 3, line 35, leave out “or the doing of such other things in relation to it as may be prescribed for the purposes of this definition”

**Clause 2—Establishment of committee to authorise processing of confidential information**

The whole structure of the Bill requires that such a Committee be established and therefore clause 2(1) should be amended to clarify that such a committee must be established rather than may be established.

**Proposed amendment**

Clause 2, page 3, line 39, after “Department” leave out “may” and insert “must”

The essential function of the Committee as outlined in clause 2 appears to be to make a balanced judgement in particular circumstances as presented to it. Namely, to judge whether the public interest served by the medical and social care purpose is sufficient to outweigh the public interest in the protection of the confidentiality of health and social care information. And on the basis of this judgement the Committee **may** to decide to authorise the processing of confidential information or **may** decide to withhold such authorisation. We consider the detail of the establishment of such a Committee to be appropriate material for Regulations.

### **Clause 3—Code of Practice**

We welcome the requirement for a statutory Code of Practice to cover processing of health and social care information.

We propose a minor amendment to clauses 3(4) and 3(5) below. We consider that ‘regard’ would be better replaced by ‘due regard’ which is a standard legal phrase which means to give a fair consideration to and sufficient attention to all of the relevant material.

#### **Proposed amendments**

Clause 3, page 4, line 22, after “have” insert “due”

Clause 3, page 4, line 26, after “have” insert “due”

### **Clause 4—Regulations**

We welcome clause 4(2) which requires a draft of the regulations to be laid before and approved by resolution of the Assembly.

#### **For further information about this written submission contact:**

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