Southern Health
and Social Care Trust

Quality Care - for you, with you

Chair
Roberta Brownlee

Chief Executive (Interim)
Paula Clarke

Our Ref: PC/CG/SMCL

7th August 2015

Marie Austin
Senior Assistant Clerk
Committee for Health, Social Services and Public Safety
Room B32
Parliament Buildings
Stormont
Belfast
BT4 3XX

Dear Ms Austin

RE: Health & Social Care (Control of Data Processing) Bill

Thank you for your letter dated 2nd July 2015.

I have responded on behalf of the Southern Health and Social Care Trust to the consultation on the proposed legislation in October 2014.

In this document I have commented with reference to specific clauses of the Bill as requested in a letter to the Trust from the Senior Assistant Clerk, Committee for Health, Social Services and Public Safety dated 2 July 2015.

Title of the Bill: In my opinion the title does not accurately reflect the circumstances in which the Bill will apply. From the title, it could be interpreted as a Bill for the control of data processing for all health and social care information in all circumstances, including the purpose for which health and social care information is originally obtained i.e. direct care. It may be that the scope of the

Bill may be improved by amending the title to reflect the purpose of the Bill – Control of Data Processing for **Secondary Purposes**.

Section 1

Section 1 (1) To provide clarity of the purpose of the Bill it may be worthwhile to include **health** and social care purposes as this is the term (rather than 'medical') which is repeated in subsection 1 (1) (a). Is it necessary to include **and**/or at the end 1 (1) (a) purpose?

Section 1 (3) I suggest amendment to 'such information **will** only be processed if authorisation is granted to the committee' rather than 'may'.

Section 1 (11) (a) (i) amendment suggested – to include both physical and mental health, thus include **'or/and'**

Section 1 (11) (b) 'social well-being' This term although inclusive may be best replaced with **'social care'** to aid consistency throughout the Bill. It is helpful that examples of services available under this term are listed.

Section 1 (13) The term medical purposes is mentioned but this may need to be clarified earlier in the Bill. In Section 1 (1) medical is mentioned but not developed or mentioned in the sub section (a) or (b) or at section 1 (11) (a) and (b).

Section 2

Section 2 (1) I suggest that **'will'** replace the term 'may' as this is an essential aspect of ensuring compliance with the legislation.

Section 3

Section 3 (1) It may be worthwhile clarifying the purpose of the Code of Practice on the processing of information **for Secondary Purposes** (to meet the requirements of the regulations).

Section 3 (6) It may be useful to include this section earlier in the Bill in order to provide clarity and to limit use to these terms rather than introduce other terms e.g. well-being which are more open to interpretation.

General Comments

It is understandable that the language used in the Bill is purposefully wide enough in scope to allow for the different circumstances that might arise where the sharing of personally identifiable information could potentially be justified. However the wide scope of the language used throughout the Bill e.g. "public interest" and "other similar circumstances" is in contrast to the language used when the overall purpose of the Bill is described - "to put in place a legal basis, with **robust checks and balances**, for the sharing information that identifies HSC users, for reasons other than direct care, in **limited and controlled circumstances**."[1]

Stronger emphasis should be given in the Bill to the fact that sharing will only take place in limited and controlled circumstances and with robust checks and balances in place.

It may be worth mentioning in the Bill that in addition to proving that the outcome will be in the interests of health and social care or in the public interest any applicant will also need to;

- prove that the results cannot be obtained without the use of personal identifiable information
- prove that it is not possible / practical to obtain consent from the individuals concerned

In my opinion it is not clear in the wording of the Bill how the balance of power between the Committee, the Data Controller and the individual would work. E.g. the Hansard report refers to the Committee as the "decision making authority"[2] but later on in the same report the Bill is referred to as "an enabling Bill"[3] whereby the Data Controller will not be required to share the information but the Bill, will instead, allow them to make an assessment if it is appropriate, in the circumstances, to share the information. The balance of power needs to be set out in the Bill and it should be made clear that the Data Controller has the ultimate

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[1] Official Report (Hansard) Health and Social Care (Control of Data Processing) Bill: DHSSPS Briefing p1

[2] Official Report (Hansard) Health and Social Care (Control of Data Processing) Bill: DHSSPS Briefing p2

[3] Official Report (Hansard) Health and Social Care (Control of Data Processing) Bill: DHSSPS Briefing p4

decision about whether the information can be shared or not **and that this can override the decision by the Committee.**

I think that it is necessary for more consideration to be given to the opt out process including the circumstances in which an opt out can be overridden and how the opt out process will be managed by the Data Controller.

The Hansard report states that an **individual's right to opt out can be overridden** by the Committee albeit in very limited circumstances, again this power does not appear clear in the Bill and if this is the case it should be clearly set out in the Bill so individuals are aware that their opt out may be overridden.

In addition, it may be appropriate to consider how the opt out will be managed. (For example if a decision was made to share the information of 8000 patients and 1800 patients decided to opt out will each of these opt outs have to be looked at on an individual basis to see if it is justifiable to override the individuals' objections in the circumstances? If so there would be concern about the resources needed to effectively manage a large number of opt outs. There is also a concern that if a significant number of individuals are allowed to opt out of sharing for a particular purpose that this will skew the results that the applicant hopes to achieve).

I wish to thank you for affording an opportunity to provide comments on the Bill. If you require further clarification of amendments please contact Claire Graham, Head of Information Governance, Southern Health and Social Care Trust (028 38 833250)

Yours sincerely

Paula Clarke

PAULA CLARKE
CHIEF EXECUTIVE (INTERIM)