

## **The Health and Social Care (Control of Data Processing) Bill – Royal College of Psychiatrists in Northern Ireland Submission to The Committee for Health, Social Services and Public Safety**

The Royal College of Psychiatrists in Northern Ireland welcomes the opportunity to submit evidence to the Committee for Health, Social Services and Public Safety in relation to The Health and Social Care (Control of Data Processing) Bill. We hope that our views as expressed herein will be of assistance to inform the Committee's on-going discussions.

The Royal College of Psychiatrists is the statutory body responsible for the supervision of the training and accreditation of psychiatrists in the UK and for providing guidelines and advice regarding the treatment, care and prevention of mental and behavioural disorders. Among its principal aims are to improve the outcomes for those with mental illness and to improve the mental health of individuals, families and communities.

The College has 370 members in Northern Ireland, including doctors in training. These members provide the backbone of the local psychiatric service, offering inpatient, day patient and outpatient treatment, as well as specialist care and consultation across a large range of settings.

This submission is made on behalf of the Royal College of Psychiatrists in Northern Ireland Executive Committee.

### **Introduction:**

The focus of the submission is broadly related to the issues of patient privacy, compulsion to release information, the Panel supervising decisions made under this legislation, stigma with mental illness and appropriateness of information sharing.

Section 1. (1) (a) *"in the interests of improving health and social care, or"*

This appears to suggest processing for service development and research. The College would expect either the Code of Practice or the terms of reference for the committee established under section 2, to give examples of the improvements which would be likely to be considered appropriate or desirable.

Section 1.(1)(b) *"in the public interest"*

As is mentioned at length in Hansard recordings of the Assembly, the term "public interest" is defined largely within case law and appears somewhat nebulous. As is so often cited "[something that is in] the interest of the public may not actually interest the public". The College has particular concerns in this regard in relation to illnesses or disorders which carry a "stigma". A main thrust of the forthcoming Mental Capacity Bill is to reduce stigma by putting mental and physical health on an equal footing, and this draft bill does likewise. However regardless of this, some illnesses or disorders are more likely to cause

harm to patients through their disclosure than others. One such example is in Addictions Treatment, where someone's dependence on a substance (be it legal or illegal) is likely to cause issues with employment, the PSNI etc. Such information is, as such, particularly sensitive – and its disclosure likewise would require very careful consideration. Another area where the public interest may conflict with the private good is that of Forensic Psychiatry; at the moment in Northern Ireland there is one Regional Secure Unit for the management of people with severe mental disorder and associated high levels of risk to others, as well as community teams undertaking care of people with these issues in the community. Again these are service users whose very involvement in these services could, if known generally, be harmful to their future health and quality of life. There is also mention in Hansard of the Fire and Rescue Service being interested in using this legislation to identify vulnerable people admitted during fires. The fear is that there is only a small step from this to the PSNI seeking access to people's medical records, where possibly incriminating information may be held confidentially. Undoubtedly the PSNI seeking such information would see it as in the public interest. However, it would be difficult to see it as in the patient's interest.

The draft legislation does include provisions for over-ruling an opt out from information sharing. Reading the associated documents it is obvious that this is to allow the extension of "notifiable diseases", e.g. were the recent Ebola epidemic to have reached Northern Ireland. However the power is there effectively to not just enable but to require sharing of information on any aspect of health and social care engagement in Northern Ireland as long as "the public interest" is served. This seems to be well-intentioned, but such legislation is open to abuse in the future by those with less pure intent.

We would suggest at least changing the wording of this section to *"in the public interest, so long as this would not subject the relevant person to risk of harm"*.

Section 1.(2)(c) *"anything done by that person in so processing the information must be taken to be lawfully done despite any obligation of confidence owed by that person in respect of it"*

The College understands that one major aim of this legislation is to reduce the likelihood of public interest secondary uses being subject to legal challenge. However, this part of the Bill, read along with subsections (8) and (9) which refer to the Data Protection Act, seems almost to be a "get out of jail free card", especially if there has been a breach in data security. The information which is being shared under this legislation is both private and sensitive to the individuals being identified by it, and were such information to be inadvertently or accidentally disclosed to unauthorised third parties (such as insurance companies or other bodies whose possession of the information may not be in the interest of the patient) then there should be appropriate penalties. Section 1.(2)(d) allows for the establishment of new offences, but these should not overrule existing offences, or if they do they should provide similar protections.

#### Section 1.(5) "*reasonably practicable*"

All reasonable steps should be taken to ensure that if anonymous or pseudonymous information can be used that it be used, and that if the patients involved could give consent that that option has been provided to them. This section of the legislation does appear to achieve this and is welcomed therefore by the College.

#### Section 1.(6)

This section appears to require annual review of any disclosures to ensure that they remain legal and that there is no other way to accomplish their aims. This is sensible and appropriate and is welcomed by the College. However, maybe consideration should be given to tying this aspect into the work of the committee established under Section 2?

#### Section 2.(1) "*may by regulations establish a committee*"

The College would suggest that the Department **must** establish such a committee and the legislation should make this a definite requirement.

#### Section 2. (3) (a) through to (e)

The regulations discussed in 2.(3)(a) through (e) appear sensible and appropriate. However the make up of the committee and the publication of its decisions should perhaps be established in this legislation, or if not then at least the hoped-for purpose of the committee should be disclosed in the legislation at this stage.

### **Summary and Conclusion:**

Overall looking at this legislation, it is likely to be worthwhile and productive for the people of Northern Ireland, and indeed if used to power medical research, for people further afield. The College would however caution some extra care to be taken in both its application and in its breadth. Recently in England the Care.data programme, which would have enabled sharing health care information with private sector bodies, has caused significant concerns among the public. The public outcry was sufficient to set it back and this has had a definite and distinct impact on Medical Informatics within England.

In Northern Ireland we are fortunate to be along the road of developing the Electronic Care Record, which is a truly wonderful innovation allowing hospital doctors and GPs to see patients' lab results, scan results, outpatient letters, medication lists, etc. It does this by connecting various computer systems and as it develops, it will also take on further roles in providing pathways for referrals etc. The equivalent system in England is the Summary Care Record. Compared to the Electronic Care Record it has far fewer functions and can provide much less information. This is because the restrictions put in place

following Care.data prevent it from having all the features of the Electronic Care Record.

Were there to be a similar public response to this Bill in Northern Ireland as there was to Care.data in England and Wales, and were similar restrictions to come into place, then the Electronic Care Record, which has been called the greatest single development in the NHS in Northern Ireland in decades, could be gutted – and the tremendous public benefit it provides undermined. As has been discussed in Committee, the intent of this legislation is not to give private bodies access to healthcare information. Despite this, the breadth of powers offered by the Bill and the fact that large amounts of intended oversight are suggested, but not firmly outlined, does mean that it is possible that the legislation could be open to abuse. The goals in the initial Consultation document are noble and the procedures discussed and planned in Committee are appropriate, but the legislation itself is very broad and its safeguards are at the moment only sketched in. Were there to be a backlash against it then it could cause harm to the Health and Social Care services across Northern Ireland.

This legislation is long overdue to cover the areas of necessary secondary use for health and social care in the region and must be viewed in the context of Data Protection legislation etc. There is also much established case law around the disclosure, in the absence of consent, of confidential information, along with a myriad of guidance (often conflicting). There are clear benefits in some secondary data use in the field of Health and Social Care, as well as problems (policing, insurance etc). However even these apparent no go areas have arguments for inclusion - eg diversion schemes for certain health conditions, the diabetic getting aggressive to police when becoming hypoglycaemic etc.

The primary legislation is the enabler, but this must be backed by adequate guidance to specify the grey areas and boundaries. There is an absolute need for a Code of Practice and/or guidelines; a central body/committee MUST be established to adjudicate requests and this would function alongside bodies like ORECNI. Such a body should be at a regional level (under the Department rather than a provider or University) to ensure consistency across the region and link to local functions.

Consent based access for research etc is preferable where this is practical (as opposed to possible) but the limits of this needs to be defined in guidance. The blanket consents sought by insurance already seem too wide and not necessarily based upon informed consent.

This represents the College's overview of this piece of draft legislation and will hopefully serve as a framework around which the College could engage in further discussion with the Committee, if required.