

## **Health and Social Care (Control of Data Processing) Bill**

### **Submission to the Northern Ireland Assembly Committee for Health, Social Services and Public Safety**

**from the Royal College of Nursing**

#### **Introduction**

- 1 The Royal College of Nursing [RCN] represents nurses and nursing, promotes excellence in practice and shapes health policy. The RCN represents registered nurses, health care assistants and nursing students across all care settings throughout Northern Ireland.
- 2 This submission builds upon and substantiates the RCN's response to the DHSSPS consultation on a proposal to introduce primary legislation for the use of Health and Social Care service user identifiable information for secondary purposes in controlled circumstances, conducted in 2014. The response was endorsed by the RCN Northern Ireland Board, the elected body responsible for the governance of the RCN in Northern Ireland. This consultation is referenced at paragraph 15 of the Explanatory and Financial Memorandum.
- 3 The RCN accepts the need to establish robust and proportionate arrangements that will achieve the correct balance between upholding the absolute security of personal confidential information relating to health and social care service users on the one hand, and the need to ensure that service developments are accurately informed by a strong evidence base on the other. As such, the RCN welcomes the intention to establish a more robust legislative arrangement for decision-making to enable a greater level of assurance to the organisation and

the individual and mitigate against the risk of successful challenge. The RCN endorses in general terms the need to control how and when the information of service users locally may be accessed in order to permit the limited use of user identifiable information for secondary purposes, in controlled circumstances, where clear and significant improvements to patient care can be expected.

- 4 The remainder of this submission addresses the wording of the draft legislation and, as requested by the Committee, is structured to address the specific clauses of the Bill. It should be noted that the RCN is offering this submission in its capacity as a trade union and professional organisation for nurses. We do not claim to offer an expert legal opinion upon the Bill and its implications.

### **Control of information of a relevant person**

- 5 The RCN shares the misgivings expressed by members of the Committee at the evidence session on 17 June 2015 in relation to the inclusion of the phrase “in the public interest” at clause 1 (1) (b). The RCN is concerned that this phrase may be too comprehensive and non-specific in scope, potentially leaving the system open to abuse on the basis of a broad and/or subjective interpretation of what may be “in the public interest”. The RCN notes the explanation provided by Departmental officials in relation to the potential use of data by, for example, the Northern Ireland Fire and Rescue Service. We do not find this explanation convincing. The legislation should apply purely to the purpose defined at clause 1 (1) (a) and the RCN recommends that clause 1 (1) (b) should be excised.

### **Establishment of committee to authorise processing of confidential information**

- 6 The key issue, of course, is establishing appropriate safeguards to ensure compliance with the legislation and the safeguarding of personal information. The RCN is unclear about how the proposed committee would discharge this function. The 2014 consultation document stated (on page 17): “Under the proposals, applicants would have to demonstrate to the advisory group that the

use of service user identifiable information is absolutely essential to the successful outcome of their work; that similar results could not be obtained by using anonymised or pseudonymised service user information; and that it is either impossible or impracticable to gain consent from every individual whose data may be used”.

- 7 It is not clear how or why the advisory group proposed in the consultation document has now evolved into the committee proposed under the Bill. More importantly, the defined purpose of the advisory group was to protect the security and interests of the service user from the non-authorised use of their personal data. The wording of the Bill, however, states that the purpose of the proposed committee lies in “... the processing of confidential information of a relevant person in prescribed circumstances and subject to compliance with prescribed conditions ...” (clause 2 (2)). It may well be that the proposed committee’s functions will mirror those of the advisory group but, if this is the case, it is not readily apparent from the wording of the Bill. There appears to be a subtle change of emphasis from protecting the interests and security of the service user to ensuring compliance with the legislation. These two objectives should be synonymous but may not always be so.
- 8 The RCN is therefore concerned to note the admission by Departmental officials during the evidence session on 17 June 2015 that the proposed committee “could” over-ride the decision of an individual to opt-out from the disclosure of data, using the “public interest” criterion. Whilst there was some discussion on this issue between members of the Committee and Departmental officials, the matter was not resolved during this evidence session. The RCN urges the Committee to seek further clarification on this issue.
- 9 Whilst arrangements relating to the membership of the proposed committee are to be defined in regulations, the RCN believes it important, in order to command public confidence, that the proposed committee must be truly independent in its composition, constitution and outlook, excluding anyone with a vested personal or professional interest in access to personal confidential data. It should act as a guarantor of compliance with the legislation and as an advocate for the rights of service users in this respect.

## **Code of Practice, Regulations, Interpretation and Short title and commencement**

- 10 The RCN has no specific comments upon the wording of these sections.

## **Concluding comments**

- 11 The primary concern for the RCN, and, we suspect, for service users and the wider public in Northern Ireland, in relation to the Bill will be ensuring that any personal confidential information accessed is done so securely and genuinely for purposes related solely to the commissioning and provision of health care services, rather than for any commercial activities. It will be essential for the DHSSPS to build confidence in this principle and overcome some of the negative perceptions and doubts that have built up as a consequence of the indifferent track record of HSC organisations in respect of their capacity to manage and store confidential personal data securely.
- 12 Stakeholder and public support for the Bill will be determined largely by an understanding of the controls that exist around the access and use of information and a general feeling that the Bill's primary purpose is to protect the security of confidential personal data, rather than to facilitate access to it. These controls relate to the security and confidentiality of the data, the fact that it must not be used to an individual's detriment, in either identifiable form or as a result of research conducted at the level of the group, and in relation to any potential commercial access to data. The RCN therefore welcomes the wording of paragraphs 8 and 9 in the Explanatory and Financial Memorandum.

## Further information

- 13 For further information about the work of the RCN in support of nursing and patient services in Northern Ireland, please contact Dr John Knape, Head of Communications, Policy and Marketing, at [john.knape@rcn.org.uk](mailto:john.knape@rcn.org.uk) or by telephone on 028 90 384 600.

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