

## **Draft NILGA evidence to the HSSPS Committee in relation to the Health and Social Care (Control of Data Processing) Bill**

This **DRAFT** evidence has been prepared in advance of an NILGA Executive Committee meeting on 14<sup>th</sup> August, at which the Committee will consider this paper. Any amendments or additional comments made by the members will be forwarded to the Committee by 5pm on 14<sup>th</sup> August.

**For further information or to discuss any of the issues highlighted, please contact Karen Smyth at the NILGA Offices. Tel: 028 9079 8972**

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Chief Executive

**6<sup>th</sup> August 2015**

### **1.0 Context**

The Health, Social Services and Public Safety Committee is calling for evidence in relation to the above Bill, which is designed to legislate for the use of Health and Social Care service user identifiable information.

This Bill is intended to provide a clear statutory framework, and robust and stringent safeguards, which will enable the use of user identifiable health and social care information, 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.

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.

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.

Where research is involved, ethical approval will also be required. Based on the experience in other areas, adopting this approach would allow delivery of significant health and social care benefits. Areas that could benefit include the management of health and social care services; improved public health monitoring; accurate and detailed disease registries; and the effective monitoring of infectious diseases.

## 2.0 Introduction

NILGA, the Northern Ireland Local Government Association is the representative body for local authorities in Northern Ireland. The membership is comprised of the 11 local borough, district and city councils and the organisation is supported by all the main political parties in Northern Ireland.

Availability of information to ensure effective coordination and integration of public services is an issue that is of growing significance for local government, particularly since councils have begun to implement their new community planning and development planning responsibilities.

Consequently, NILGA is pleased to be able to respond to this consultation and would like to thank the Committee for the opportunity to comment. We trust that the views of local government will be taken into account.

## 3.0 General Comments

**NILGA supports the proposal to bring forward legislation to enable the Department to regulate the use of service user information for secondary purposes in controlled circumstances.**

Councils, as stated above, are preparing for their new community planning and development planning responsibilities, and are in a concentrated phase of evidence gathering and community engagement, to inform the baseline for these planning cycles. A great deal of the information councils use is gathered from the Northern Ireland Statistics and Research Agency 'NINIS' site, which gives relevant demographic information, in most cases, down to 'super output' areas and at least, down to council 'ward' level.

Although councils currently sit outside the 'Health and Social Care family', it is evident that across the UK, more emphasis is being placed on preventative health care, in which councils play a key role. Given the new powers and functions recently passed to councils, this role for councils in Northern Ireland is likely to grow, and NILGA is keen to explore how better partnership working can be developed, including through the sharing of appropriate data at appropriate local levels.

Health and social care data is often available at Trust level, and one of the reasons for this is the need to protect the identity of service users. It would be extremely helpful to examine how best to provide Health and Social care information so that need can be addressed within the planning processes for the new 11 council areas, even though it is highly unlikely that councils will require anything other than anonymised or pseudonymised data. More detail available at local level could help pinpoint particular 'hotspots' for health issues, facilitating targeted action.

## 4.0 Clause by Clause Comments

### **Clause 1: Control of information of a relevant person**

NILGA is supportive of the content of this clause, which provides the Department with regulatory making powers in connection with the processing of information held within the Health and Social Care sectors, where this is in the interests of the improvement of health and social care, or is in the public interest.

We would highlight to the Committee that councils may seek to obtain and use information in the public interest, and would request that the Committee ensures that councils are considered fully, within the information sharing context

NILGA would also acknowledge the importance of ensuring that contraventions of the Bill and associated Regulations are prevented and discouraged, through the enabling of a Regulation specifying relevant offences.

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

NILGA is supportive of Clause 2, which provides the Department with the power to make regulations establishing a new committee to authorise the processing of confidential information under the Bill.

It will undoubtedly be necessary for the committee established under clause 2 to consider how it will deal with applications from councils or community planning partnerships in a strategic and efficient manner.

As this clause also enables the Department to set out in regulations the make-up of the committee, and its procedures, NILGA would respectfully request that the Assembly HSSPS Committee gives full consideration to the potential for a senior local government representative (e.g. a Chief Executive) to have membership of the committee. It is the view of NILGA that councils should be considered a governmental partner in tackling the public health issues faced in Northern Ireland

**Clause 3: Code of Practice**

NILGA is supportive of this clause, which provides that the Department must prepare and publish a code of practice on the processing of information, and sets out how this may be reviewed.

This clause also places an obligation on Health and Social Care bodies, and any other person providing health and social care, to have regard to this code of practice. NILGA particularly welcomes Clause 3 (5), and would highlight to the Assembly HSSPS Committee, the need to consult all organisations potentially affected by requirements in the Code, when drafted.

**Clauses 4, 5 and 6**

NILGA has no comments to make in relation to Clauses 4, 5 and 6.

**4.0 Conclusion**

Local government is already in the process of building stronger relationships with the health and social care sector. As community and development plans are prepared and implemented, councils and health and social care organisations are working together to achieve the social, environmental and economic wellbeing of local communities. NILGA and councils are already communicating regularly with NISRA, and we look forward to a more robust system for HSC information sharing, in the public interest.

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