

# Law Centre response to Consultation on use of H&SC information for secondary purposes

## About Law Centre (NI)

Law Centre (NI) works to promote social justice and provides specialist legal services to advise organisations and disadvantaged individuals through our advice line and our casework services from our two regional offices in Northern Ireland. The Law Centre provides advice, casework, training, information and policy services to our member organisations, including in the areas of mental health and community care.

## Need for legislation

The Law Centre agrees with the proposal to bring forward legislation to regulate the use of service user information for secondary purposes in controlled circumstances. As what is being proposed is a set aside of the common law duty of confidentiality, it is important that the proposed legislation contains robust safeguards to protect the rights and interests of service users, particularly those who are vulnerable in that they are less able to act to protect their own rights and interests than others. The creation of a clear statutory framework is needed as currently the legality of much secondary use of confidential health and social care information is at best unclear. Without such a clear statutory framework, it is unlikely that Northern Ireland complies with the 'in accordance with the law' requirement of article 8 of the European Convention on Human Rights.

The Law Centre agrees with option 5 as the preferred option for legislation, namely to introduce NI legislation similar to sections 60 and 61 of the G.B. Health and Social Care Act 2001 (which were replaced by sections 251 and 252 of the National Health Service Act 2006) but include the sharing of social care information. However, we have concerns about suggested basis in the Data Protection Act 1998 for the lawfulness of inclusion of social care information as outlined below.

## Establishment of an advisory group

The Law Centre thinks that there is a need for a flexible mechanism for considering applications to use confidential information for secondary health and social care purposes without consent on a case by case basis. Legislating specifically for every potentially valid secondary use would be cumbersome and not likely to serve the public interests which secondary uses and research uses aim at.

To function as an effective safeguard of the rights and interests of service users, it is essential that the membership of any advisory group is balanced and reflects a broad range of perspectives. Such a group should of necessity include service user representatives and lay members in sufficient numbers to ensure a balanced view of issues. Consideration should be given to a requirement that the majority of members should not be H&SC staff to ensure the advisory group does not end up effectively being a judge in its own case. Given the need for advice to comply with other

legislation, members with expertise in data protection and human rights should be required for the group.

It is essential that any such advisory group be adequately resourced to ensure that applications can be processed quickly. The model developed in England and Wales has evolved to provide 'up front' support to bodies planning applications which helps to improve the quality of applications and thus to keep the running cost of the advisory group down.

### **Content of the legislation**

A considerable body of good practice has evolved in England and Wales over many years through the work of the Confidentiality Advisory Group and its predecessor bodies, the Ethics and Confidentiality Group and the Patient Information Advisory Group. Consideration should be given to the inclusion of some of this good practice in the proposed legislation.

We refer the Department to the Standard Conditions of Approval of the Confidentiality Advisory Group.<sup>1</sup> In particular, consideration should be given to the inclusion of condition 8 which states: 'The wishes of patients who have withheld or withdrawn their consent are respected.' This right to 'opt out' is an important safeguard. Inclusion of this right in the legislation would make a significant contribution to the maintenance of public confidence in the handling of deeply sensitive personal information by the health and social care sector. A right to opt out provides a residual measure of control to service users who have particular concerns about the use of their information. Whilst there may be rare circumstances in which the public interest to be served is so great that a right to opt out should not be available, such circumstances should be specifically provided for other than through the advice of the group alone.

### **Other comments:**

#### **Human Rights Act 1998**

Article 8 of the European Convention on Human Rights (ECHR) protects the privacy of health and social care information<sup>2</sup> (, MS v Sweden). An interference with this right may in certain circumstances be justified. However, it is the interference which must be justified, not the non-interference. To ensure full compliance with the ECHR, the legislation should contain a rebuttable presumption of non-use and non-disclosure. This would make it clear that it falls to those making an application for the secondary use of service user identifiable information to establish both the necessity and proportionality of what is being proposed. Such a statutory presumption would also

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<sup>1</sup> Available at: <http://www.hra.nhs.uk/documents/2013/08/cag-standard-conditions-of-support.pdf>

<sup>2</sup> Z v Finland, (22009/93) 25 February 1997; MS v Sweden (74/1996/693/885) 27 August 1997.

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appropriately frame the starting point and discussions within the advisory group. Without the burden of proof being framed in the statute, there is a significant risk that the 'jurisprudence' of the advisory group would drift towards disclosure and use as being the default position unless it is established otherwise.

### **Data Protection Act 1998**

Whilst the processing of sensitive personal data without explicit consent for 'medical purposes' is possible through reliance on Schedule 3 (8), it is not clear how the envisaged reliance on Schedule 3 (7) will suffice to make lawful the processing of social care information for secondary purposes. Paragraph 7 of Schedule 3 does permit processing for 'the exercise of any functions of ... a government department'. However, it is not clear how the provision of Health and Social Care services being a function of DHSSPS carries through to data processing which is actually carried out by Trusts, GP practices or bodies such as the RQIA. Greater detail would need to be provided on this proposed reliance in legal terms for the Law Centre to be assured that the proposals are compliant with the Data Protection Act.

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