

The NI Electronic Care Record - Confidentiality and Consent Considerations

An advisory note prepared by Privacy Advisory Committee (N. Ireland)

Introduction

Privacy Advisory Committee (PAC) recently issued a Position Statement¹ on the Northern Ireland Electronic Care Record (NIECR). The purpose of the present paper is to provide further comment and advice on the confidentiality and related consent obligations applicable to the NIECR and, from a confidentiality perspective, what we consider to be appropriate preconditions for current and potential future developments in the NIECR.

In our earlier paper we presented our considerations of the data protection, privacy and confidentiality obligations in relation to the NIECR proposals for direct care.

Current NIECR Proposals

It is our understanding that current proposals are to bring together in a single record, for direct care only, service user information held separately in existing regional and HSC Trust databases, such as patient administration information, radiology and laboratory data, together with the extraction of primary care information on allergies and medications, the latter currently being held within the Emergency Care Summary.

In addition it is proposed to include the discharge correspondence currently being held in Patient Centre, that is information which has been uploaded from hospital Patient Administration System. It is our understanding that this information does not include highly sensitive information, such as information relating to sexual health, mental health, and sensitive personal and social information.

Recommendations in relation to current proposals

a. Creation of the NIECR

GP extraction. As stated in our Position Paper, the NIECR should reflect the current opt-out provisions for ECS information.

Laboratory Information. The bringing together in a single NIECR record of information already held centrally in separate databases does not, in our view, present any new issues from a confidentiality perspective.

Hospital discharge correspondence. While the incorporation of discharge correspondence into a single NIECR record will not include highly sensitive information, it is a significant departure from current practice.

We consider the proposed public information campaign on the NIECR to be a suitable means for communicating the proposed changes. There should be sufficient detail available so that individuals can make informed choices. While we anticipate that the proposed mail drop needs to be kept simple and uncluttered, it should provide a pointer to where the necessary additional information can be accessed. This should include, for example, information on the proposed inclusion of hospital correspondence.

Consideration needs to be given to how to respond to requests not to have information included in an individual's NIECR, however unlikely such requests may be. It may not be possible or practicable to selectively exclude, for example, hospital correspondence. Choice may therefore be around whether or not to have a personal NIECR. The Code of Practice² advises that such kinds of choices should normally be respected, even though care and treatment may be compromised.

b. Access and permission to view

PAC supports the proposed on-screen consenting options for viewing the NIECR for direct care. Exceptions to the usual consent to view include emergency situations, where a person is incapable of consenting due to impaired consciousness, and other situations of mental incapacity. In such situations that person's best interests should normally guide decision-making. Where a child or young person is incapable of giving consent the consent of a parent should usually be sought.

Future development of the NIECR

The PAC Position Statement advises that any subsequent proposals for the further development of the NIECR, for example the addition of new information or sources or the creation of a single health and social care record, require separate additional considerations of the privacy, confidentiality and consent issues that are likely to arise.

One important issue is the possible incorporation of highly sensitive personal identifiable health or social care information into the NIECR. The potential benefits for service users are likely to be similar to the benefits already demonstrated for less sensitive information. Nevertheless the duties of confidentiality are also considerable.

Recommendations in relation to highly sensitive information

a. Definitions

PAC advises that consideration should be given to establishing an acceptable definition and specification of "highly sensitive health and social care information". As stated above, we consider this should include mental health and sexual health. In addition to health related matters, given the integrated context of our system of care, there are likely to be highly sensitive issues within social care and social work.

b. Proposed incorporation of highly sensitive information within the NIECR

PAC advises that an individual's express consent should normally be sought, obtained and recorded as a prerequisite to the inclusion of any highly sensitive information within their NIECR.

c. Access

PAC advises that express consent should normally be a prerequisite to viewing highly sensitive information. Any permitted role-based or group-based access to non-highly sensitive information should not automatically allow access to highly sensitive information.

**Privacy Advisory Committee
February 2013**

1. The Electronic Care Record including the Emergency Care Summary. A Position Statement prepared by Privacy Advisory Committee (N. Ireland) 2012.
2. Extract from Code of Practice on Protecting the Confidentiality of Service User Information

CHAPTER 2. Service User Information

Consent

2.7 If the service user refuses to consent to disclosure of personal information, the information cannot be disclosed, unless, exceptionally, a justification other than consent exists. Staff should discuss with the service user why he/she thinks that disclosure is in the service user's best interests and the potential disadvantages that may arise. Unless there is an overriding public interest justification, information should not be disclosed on a "best interests" basis where an adult with capacity refuses to consent to disclosure.