Citizens Information Board
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Draft Information Governance and Management Standards for the Health Identifiers Operator

Submission by the Citizens Information Board (April 2015)

Introduction

The Citizens Information Board (CIB) welcomes the opportunity to comment on the Draft Information Governance and Management Standards for the Health Identifiers Operator. The current consultation process is particularly important because of the fact that a Unique Identifier system for health and social care is being introduced for the first time in Ireland.

CIB has previously[1] stated it's view that the use of a Health Identifier system has the potential to provide more effective linkages between the primary and secondary health care domains and between the public and private sectors and should also eliminate the need for people using health and social care services to provide personal details at every contact with the system. The use of a Unique Health Identifier system for both individuals and service providers has the potential to facilitate better service and care planning for individuals.

The CIB notes that an analysis of experience in other jurisdictions has been carried out in identifying the core components of the Irish system.

Ensuring Privacy and Confidentiality: Key Considerations

The obvious value of having an Individual Health identifier (IHI) system must be balanced by the need to ensure privacy and confidentiality in accordance with both data protection legislation and each individual's basic right to privacy as recognised by the European Convention on Human Rights and implied in the Irish Constitution.[2]

The fact that the Health Identifiers Operator will be required to adhere to the rules governing personal information set out under Data Protection legislation is important. In particular, keeping the information safe and secure and keeping it accurate and up to date will be an important aspect of the system.

While it is stated that Health identifier records need to be kept safe and secure under legislation (the Data Protection Acts and the Health Identifier Act 2014), the fact that

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[1] http://www.citizensinformationboard.ie/publications/social/downloads/HIQA_National_Demographic_Dataset_CIB_Submission_April2013.pdf

[2] http://www.justice.ie/en/JELR/WkgGrpPrivacy.pdf/Files/WkgGrpPrivacy.pdf

all systems that collect, use, store or disclose personal information run some risk of a breach of the privacy of personal information remains a core concern.

Since the two national registers of health identifiers which are to be established (the National Register of Individual Health Identifiers and the National Register of Health Services Provider Identifiers) are a significant departure from current practice, it will be essential that an adequate support and administrative infrastructure is put in place at the outset.

The inclusion of PPSNs on IHIs, while understandable for the reasons given (to allow the central IHI computer system to be created and subsequently updated from existing trusted sources and to get the best use out of the existing public infrastructure) presents challenges from a data protection and privacy perspective. It will require that great care is taken to ensure that the distinction between people's PPSN and their Individual Health Identifier is clearly stated and understood by all involved. Also, centrally relevant in this regard is the need to ensure that a person's PPSN is not inadvertently used in a manner that breaches either people's right to privacy or Data Protection legislation.

The intention that a person's PPSN will never be provided to a person's health service provider when they look at his/her IHI record and, therefore, never included in a person's health care record will be difficult to implement in practice. This also applies to the stated intention that it will not be possible for anyone to look up a person's PPSN number using his/her IHI.

How IHIs will interface with PPSNs in the longer term as public service delivery becomes more integrated and organised around individuals is an important factor.

Also, it would be useful if there was some reference to how the Health Identifiers system being introduced now would relate to the longer-term goal of having a national electronic health record system similar to ones that operate in other jurisdictions.

The provision that no medical or clinical information will ever be stored on a person's IHI identifier record is of crucial importance. In this regard, it will be difficult to manage the situation where health services providers will have access to a person's IHI when communicating with other health service providers about his/her care.

The rationale for including agencies (additional to service providers) on the list[3] that will have access to the National Register of Individual Health Identifiers is not clear in relation to some of the agencies listed. Neither is it clear how information on the Register will be used by these agencies. This point also applies to organisations that may use IHIs for secondary purposes, such as health promotion, health service management or research.

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[3] Chief Inspector of Social Services; Child and Family Agency; Health Research Board; Irish Blood Transfusion Service; Irish Medicines Board; Mental Health Commission; National Cancer Registry Board; State Claims Agency.

The question of consent is relevant in that, generally speaking, as far as is practicable and possible, all those whose personal information is put on a database should understand what is involved and give their consent. A matter of particular concern is how the situation of people who cannot give consent or where it is unclear whether or not they are able to give consent to have their personal details in an IHI is to be dealt with. This is important from consideration from a human rights perspective and one that needs to be addressed.

Specific Consultation Questions

Question 1: Is the language used clear?

Overall, the language used in the Draft Document is clear and, in general, the standards and features are clearly stated. However, what is not clear is how the Health Identifiers Operator will know whether or not they are properly implementing the Standards and who is responsible for monitoring their implementation. It would probably be helpful if some Check Questions were included.

Also, what is not clear is how health and social care providers are to be defined and understood. The use of the generic term ‘health and social care’ throughout requires further elaboration and clarification with specific reference as to which service providers are included. For example, are private nursing homes, residential services for people with disabilities and community-based social care organisations to be included as service providers that will have access to the National Register of Individual Health Identifiers.

The CIB suggests that active consideration should be given to changing the title from ‘Health Identifier’ to ‘Health and Social Care Identifier’

Question 2: Is the layout and design of the Draft Standards clear, easy to follow and understand?

The use of a thematic framework (5 Themes and 12 Standards with stated features under each standard (59 in total) is helpful. However, the themes as set out are somewhat disparate and do not fully reflect the stated need to for an integrated system of governance and management. It would be useful if more cross-referencing between different standards and features included under each of the 5 themes could be included. This would assist Health Identifiers Operator staff in navigating their way through what by its nature will a complex undertaking.

Question 3: Do you feel that the order and structure of the standards is logical?

While the concept of person-centred support should be central to all services, it does appear to be somewhat out of sequence in being included as Theme 1 in this set of standards, given that the primary service focus is on a structure rather than a personal service. Consideration should, therefore be given to including this as, perhaps, *Theme 4.*

Question 4: Do you feel the draft standards protect the confidentiality and privacy of your health identifier record?

Since people’s IHI will be accessible by health service providers, both public and private, (and presumably by social care providers) when they provide a health or social care service to an individual, it will be difficult to ensure the privacy of the system.

Given the central importance of privacy and confidentiality, this needs to be made more central throughout the Standards. Features relating to the actual carrying out of privacy impact assessments (how this is to be conducted) should be included under Standard 1.1.

Question 5: Do you feel that all important topics have been covered or are there any topics that should be included or excluded?

The Standards cover a wide range of governance, organisational and administrative matters and this is very welcome. However, there are some gaps. Overall, there would appear to be insufficient attention given to:

(i) The requirements for setting up interactive databases that ensure privacy and confidentiality, and

(ii) How service providers are expected to engage with the system and what the Health Identifiers Operator needs to do to achieve this

Question 6: Having read the background information, do you feel that you understand the background to these draft standards? Is enough background information provided?

Considerable background information is provided about the rationale for and the process adopted in developing the Unique Health Identifier concept in Ireland. There is, however, insufficient attention given to the service provider aspect of the system and the interface between a very disparate range of health and social care providers (which will be included on the National Register of Health Service Provider Identifiers) and the National Register of Individual Health Identifiers.

Also, while the potential advantages of the Unique Identifier System for the various stakeholders are set out comprehensively, there is little reference to the difficulties and challenges inherent in operationalising the system. The CIB believes that these need to fully identified and acknowledged at the outset.

Question 7: Do you feel that additional guidance on any of the concepts contained in the draft standards should be provided? If so, what additional guidance do you feel is necessary?

There is a need for a clear statement on whether or not an individual can initiate or access his/her IHI and, if so, a Standard and features as to how the Health identifiers Operator is to manage this interface.

There is a need, as already stated, for guidance on how people who may be unable to give consent, or for whom it is not clear whether or not they can give consent, because of cognitive impairment are to be dealt with. The provisions of the forthcoming assisted decision-making legislation will be pertinent in this regard.

Question 8: Are these draft standards `fit for purpose' and appropriate for use by the health identifiers operator?

Ideally, there is a need for more work on developing a system of auditing by the Health Identifiers Operators in relation to how well they are meeting each ‘feature’ of each Standard. This raises significant logistical and resource questions.

Ideally, questions relating to the actual implementation of the Standards would be useful, e.g., how do we know whether or not we are complying with the differend standards and related features.

Question 9: What other areas of standards are needed to support the introduction of individual health identifiers and health services provider identifiers?

Consideration should be given to including a Standard to indicate how health and social care providers are to be identified and understood, what the criteria for inclusion are and what are the expectations in terms of service providers engaging with the system.

Theme 1: Person-centred support

The inclusion of ‘person-centred’ as a Theme is welcome. However, the term needs to be better defined in terms of what it means in the context of the Health Identifiers Operator which by its very nature will be systems-focused.

There is, as already stated, a need to address the matter of how the situation of people who cannot give consent or where it is unclear whether or not they are able to give consent to have their personal details in an IHI is to be dealt with. There would probably be merit in addressing this matter under the Person-centred Support theme and including appropriate standards for this purpose.

Theme 2: Leadership, governance and management

Some reference should be made to a requirement for specialist training for both Health Identifier Operator staff and for social and health care providers, the latter in relation to using the Health Identifiers system.

An important question is how will the provisions for reviewing the system based on the implementation of a quality assurance framework (Feature 2.1.7) be implemented?

Theme 3: Use of information

- Provision should be made for how both paper and electronic information exchanges between service providers and the Health identifiers Operator are to be managed and additional Features included accordingly;

- A Standard (and related Features) should be included for developing and maintaining integrated linkages between information held by service providers, in particular, GPs and acute hospitals, and the Health Identifiers Operator.

The following additional Feature is suggested:

3.1.8 "*There are effective information technology links between the Health Identifiers Operator and service providers so that information is transferred in an integrated and secure manner and in accordance with data protection legislation.*"

Theme 4: Use of resources
Some Guidance should be available on how available resources should be prioritised to support the phased implementation of the system. For example, under the theme, *Leadership, governance and management,* there could be a requirement for the Health Identifiers Operator to put in place a phased implementation plan.

Other General Comments by the CIB
The CIB identifies the following as key questions to be addressed in progressing the implementation of the Information Governance and Management Standards for the Health Identifiers Operator:

1) What are the training implications and how will these be catered for?

2) What are the IT requirements with particular reference to the myriad of health and social care providers at local level and how are these to be addressed?

3) Related to the above, how will the potential interface between the Health Identifiers Operator and other databases, e.g., the PPSN system, be managed to ensure privacy and confidentiality?

4) How are the public to be assured that the Unique Health Identifier System is in their best interests from a health and social care management perspective and how will the inclusion of the PPSN be managed in terms of public perception ?

5) Will individuals be able to access and amend their own IHI and, if not, should they be able to do so?

6) Who will decide which health /social care professionals will be on the National Register of Individual Health Identifiers and who will have access to the National Register of Health Services Provider Identifiers?

7) How will the situation of people who cannot give consent or where it is unclear whether or not they are able to give consent to have their personal details in an IHI be dealt with?

8) How will the Health Identifiers Operator ensure that any information provided for research or statistical purposes will be used **only** in an anonymised

format?

9) There is a need to assess current local health information systems in terms of their potential to integrate with the two Health Identifier databases?

The CIB agrees that the proposed Health Identifier system is a significant stepping-stone in a move towards a more integrated and accessible health and social care system. However, CIB is of the view that the introduction of the system must be based on clarity of purpose and terminology and clarity about how it is to be used.

The CIB takes the view that access to IHIs should not commence until other parts of the infrastructure are in place, including, in particular, a full listing of the health and social care practitioners and organisations that can access the system. This latter listing is important in the case of, for example, private nursing homes and community-based social care organisations.

The CIB considers that the introduction of the Health Identifier Registers will need to be accompanied by education and training measures to ensure that the systems are operated efficiently and effectively.

Finally, the CIB notes the somewhat technical nature of the provisions as set out in the Draft Standards and suggests that there is thus a need for a Plain English audit of the Guidance in order to ensure that it is easily understood and interpreted in the same way by all users. This is particularly important because the Health Identifier concept will be new to many citizens and service providers.