Draft Information Governance and Management Standards for the Health Identifiers Operator in Ireland

Health Information and Quality Authority An tÚdarás Um Fhaisnéis agus Cáilíocht Sláinte

Consultation Feedback Form

DATE: March 2015

Your views are very important to us. We would like to hear what you think about the draft standards. Your comments will be considered and will inform the development of the final Standards.

The **Draft information governance and management standards for the health identifiers operator in Ireland** contain standard statements and examples of how each standard could be met.

You can comment on one or all of them, or you may wish to make general comments. When commenting on a specific standard or feature, it would help us if you tell us the reference number of the standard or feature (for example, Standard 2.1 or Feature 2.1.2) that you are commenting on.

The closing date of the consultation is Friday 24 April 2015 at 5 pm.

You can email or post a completed form to us. You can also complete and submit your feedback on www.higa.ie.

About you

Name	Cian O'Dowd
Contact details ¹	10 Fitzwilliam Place, Dublin 2;
	Tel: 01 676 7273; Email: codowd@imo.ie
Date	17 April 2015
Are you commenting on behalf of your organisation or in a personal capacity?	Organisation ⊠ Personal □
Organisation	The Irish Medical Organisation (IMO)
(Please include name of organisation if making this submission on behalf of your organisation)	

¹ We are requesting your contact details as we may need to contact you to seek clarification on specific aspects of your feedback.

Layout of this public consultation form

The consultation document presents the **Draft information governance and management standards for the health identifiers operator in Ireland** for public consultation and feedback.

The Standards are intended to provide information governance and management standards for the health identifiers operator, that is, the business unit with the HSE mandated to set up and operate the **National Register of Individual Health Identifiers** and the **National Register of Health Services Providers Identifiers**. The main purpose of these draft standards are to protect the privacy and confidentiality of service users' and health service providers' personal information.

We would like to hear your views on the use of these draft standards as part of an overall strategy to improve patient safety through the effective and appropriate use of health identifiers. We would like to find out what you think of the draft standards. For example:

- Do you think that all the areas you consider important are covered?
- Are the standards and features clear and easy to understand?

This public consultation form is divided into two sections:

- General feedback questions which ask for your comments and feedback on the consultation document <u>in general</u> under different headings such as 'layout and design', 'content', 'applicability' and so on.
- Specific feedback questions which asks for your feedback on the consultation with respect to the <u>specific standards and features</u> that are presented under each theme.

General feedback questions

Layout and Design

Please note that these are draft standards for consultation. The final document may contain different colours and images where suitable.

Question 1: Is the language used clear?

Please comment:

Yes.				

Qu	estion 2:	Is the layout of the standards clear, easy to follow and understand?
Ple	ase comment:	
	Yes.	

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

Content

One of the benefits of using health identifiers for both service users and health service providers is an improvement to patient safety. It is vital that the **National Register of Individual Health Identifiers** and the **National Register of Health Services Providers Identifiers** are set up and maintained so that appropriate accountability exists within the health identifiers operator, personal information is kept secure, accurate and confidential, resources are managed in line with the objectives of the two registers and the workforce have appropriate skills, attributes and competencies.

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

Please comment:

Little guidance is provided in these Draft Standards to describe how the confidentiality and privacy of health identifier records, and associated data, is to be protected.

Data protection requires continuous and structured reviews of security arrangements, a commitment to use of the latest and most advanced security technologies, an identified person who has overall responsibility for the auditing, improvement, and maintenance of systems utilised in the protection of all data processessed by the health identifiers operator, and recruitment strategies that aim to ensure the employment of persons with appropriate experience, qualifications, and skills to guarantee the safeguarding of personal data must be utilised.

Firm commitments are not provided under these Draft Standards to abide by such practises, and any Draft Standards that fail to expressly give these undertakings will exhibit shortcomings in their goal, to protect the confidentiality and privacy of health identifier records.

Furthermore, little clarity is provided in regard to what information persons employed by health providers will have access to.

Comprehensiveness

These draft standards are intended to be used by the health identifiers operator to encourage accountability, decision making, risk management and good information governance practices.

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

Please comment:

Greater focus should be placed on the means through which health practitioners, and other bodies granted access to the National Register of Individual Health Identifiers obtain information and on the security framework that governs such access. There is little clarity given as to which persons employed by health providers are entitled to access the National Register of Individual Health Identifiers, and how much information, if any, may be displayed in addition to the Individual Health Identifier when searched.

Furthermore, while these Draft Standards relate primarily to the governance of the health identifiers operator, this operator should be cognisant of, and engaged in preparation for, the potential use of Individual Health Identifiers by healthcare providers outside of the state to reference patient records held by healthcare providers in Ireland. The Standing Committee of European Doctors (CPME), has produced a policy, *Ensuring the Secure Use of Telemedicine and E-Health Applications in an Integrated Europe*, which focuses on the crossborder use of telemedicine and e-health in Europe, and how it can be achieved in a manner that offers robust protection of the privacy of patients' data. The IMO advises that any health indiffers operator should put in place processes to prepare for the use of Individual Health Identifiers by bodies outside of the state and should consider the integration of the standards suggested in this CPME policy in such processes.

Question 6:		Having read the background information, do you feel that you understand the background to these draft standards? Is enough background information provided?
Ple	ease comment:	
		ealth and health provider identifiers.
	uestion 7: ease comment:	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?
	Please see ans	swers referring to Themes 1 to 5 inclusive.

Applicability

These standards are intended to be used by the health identifiers operator; that is, the business unit within the HSE required to set up and operate the **National Register of Individual Health Identifiers** and the **National Register of Health Services Providers Identifiers**.

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

Please comment:

The standards included are largely appropriate for use, however the amendments and additional guidance specified in the various answers provided in this consultation response would improve the focus on data protection.

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

Please comment:

Please see answers referring to Themes 1 to 5 inclusive.

Specific feedback questions

In this section, please provide your comments with respect to the standard statements and features that are presented under each theme. Please relate your comment to a specific standard or feature number (for example, Standard 1 or Feature 3.2.3).

Please consider the following questions as part of your review:

- Can these draft standards and features be applied to the health identifiers operator in a manner that supports good information governance and management?
- In your opinion are the standard statements and the features that follow each standard statement clear and easy to understand?

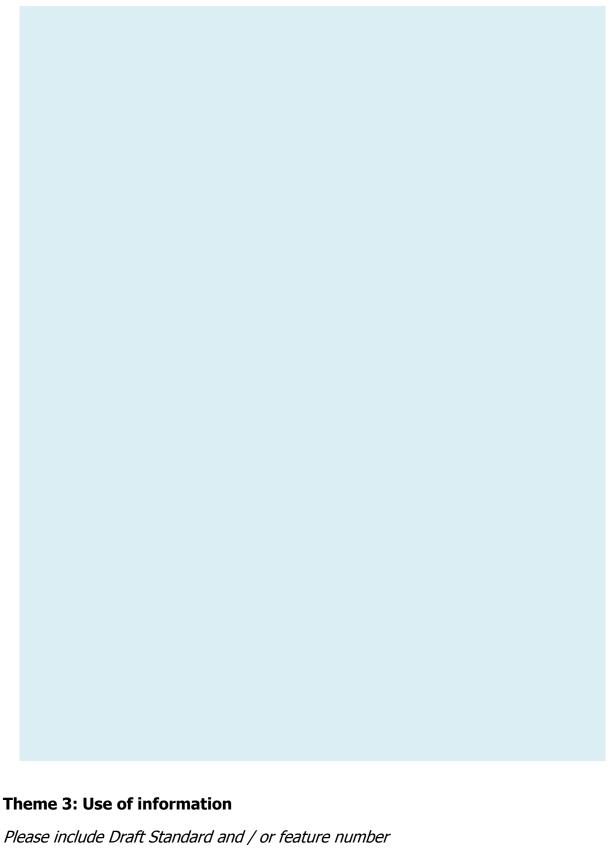
Theme 1: Person-centred support

Please include Draft Standard and / or feature number

Regarding Standard 1.2, an approach focused on "person-centred support" must provide for a robust two-way communicative structure and standards should be established within this Theme to provide for an information service that endeavours to respond to all requests from the general public or patients for information about the National Register, Individual Health Identifiers, or any associated processes or structures.

Standards 1.2.1 to 1.2.3 refer only to communication from the health identifiers operator, and contain no undertaking to engage in discourse with members of the public or patients.

Theme 2: Leadership, governance and management Please include Draft Standard and / or feature number Omitted from this Theme are standards on leadership, governance, and management structures for areas that are of considerable importance to the effective performance of a health identifiers operator. These standards lack reference to an identified person who has overall responsibility for the auditing, improvement, and maintenance of systems utilised in the protection of all data processessed by the health identifiers operator. It is important that there is clear accountability and process ownership by an identified individual enshrined within standards, and that governance structures of this element of the operator's duties are clearly established. Similarly, these standards lack reference to an identified person who bears responsonsibility for the recruitment of suitable personnel, and their subsequent training, to ensure that the highest standards of knowledge, skill, and ethical conduct are utilised in the performance of the health identifiers operator's functions.



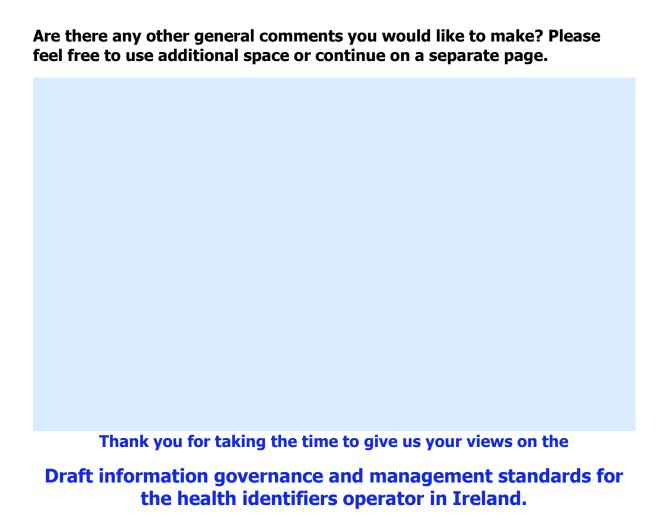
Standard 3.1 relates to the maintenance and review of the privacy of health identifier records contained in the national registers. It is crucial that effective resources are put in place, both financial and human, to ensure the highest level of security is afforded to processed data. This should mean that the most up to date technology is utilised in the encryption and safeguarding of data, and that suitably trainined persons are employed for the purposes of maintaining and reviewing ongoing privacy and security arrangements. Acces to the registry by health service providers should be secured and accessible only through the use of eIDs that are 1999/93/EC compliant. Additionally, in relation to Standard 3.2, reviews of possible duplicates within the registry should take place at regular intervals to effectively reduce the likelihood of an incorrect identifier being utilised.

Theme 4: Use of resources

Please include Draft Standard and / or feature number

The safeguarding of data and the privacy of patients should be explicitly mentioned within this Theme. Standard 4.1.4 desribes what criteria are used to inform decisions on resource allocation, yet the safety of data is not expressly mentioned. This must be considered a priority concern and should be listed amongst the criteria in this section.

Th	neme 5: Workforce
Ple	ease include Draft Standard and / or feature number
	Standard 5.1 is the solitary standard contained within this Theme and relates to the delivery of regular, evidence-based training programmes to its own workforce. There is no standard to ensure that recruitment practices focus on employing persons with a skillset or experience suitable for the effective discharge of duties. This is of particular importance with regard to IT securities, where a high level of pre-existing technical knowledge is required to adequately safeguard data. Standards should be developed under this Theme, therefore, to ensure that recruitment practices that improve the organisational capability are instigated.



Please return your form to us either by email or post.



You can download a feedback form at www.hiqa.ie and email the completed form to standards@hiqa.ie



You can print off a feedback form and post the completed form to:

Health Information and Quality Authority,

Draft information governance and management standards for the health identifiers operator in Ireland

George's Court,

George's Lane,

Smithfield,

Dublin 7



If you have any questions on this document, you can contact the consultation team by calling (01) 828 6748.

Please return your form to us either by email or post before Tuesday 21 April 2015 at 5 pm

Please note that the Authority is subject to the Freedom of Information (FOI) Acts and the statutory Code of Practice regarding FOI.

Following the consultation, we will publish a paper summarising the responses received. For that reason, it would be helpful if you could explain to us if you regard the information you have provided as confidential. If we receive a request for disclosure of the information we will take full account of your explanation, but we cannot give an assurance that confidentiality can be maintained in all circumstances.