

## Consultation on Draft Information Management Standards for National Health and Social Care Data Collections

*Submission to the Health Information and Quality Authority by the Citizens Information Board (July 2016)*

### Consultation feedback form

#### General Feedback Questions

#### Layout and design of the standards

**Q. Do you feel that the order and structure of the standards is logical? Is layout clear, easy to follow and easy to understand?**

Please comment:

The use of a thematic framework (6 Themes and 11 Standards with stated features under each standard) is clear and helpful. However, Theme 1, 'Person-centred' might be better named 'Protecting Personal Data', given that the primary focus is on a system or structure rather than a personal service.

It would be helpful to have more discussion in the document on how the Standards will enhance data collection and reporting by individual organisations and nationally. This could be done in the Purpose of the Standards Section (1.6). It is likely that compliance with the Standards will be more easily attained where there is consensus about their overall contribution to health and social care data collection nationally.

#### Comprehensiveness

These standards apply to all national health and social care data collections in Ireland.

**Q. Do you feel that all important topics have been covered, or are there any topics that should be included or excluded? Should additional guidance on any of the concepts be provided?**

Please comment:

The Standards cover a wide range of governance, organisational and administrative matters and this is necessary and welcome. However, there would appear to be insufficient attention given to research ethics requirements, particularly as these apply to people with cognitive impairment and their ability or not to give consent. Also, the implications of the provisions for supported decision-making in the Assisted Decision-making (Capacity) Act 2015 need to be factored into the Standards.

There is a need for more emphasis on how people are to be assured that their health and social care data is being held securely in compliance with legislation. and to be informed of what data is held about them.

Another important point is how the matter of data matching and the interoperability of data from different sources are to be handled and managed from a privacy and confidentiality perspective.

## Driving quality improvement

Service users, the public, service providers and healthcare professionals expect national health and social care data collections to produce quality data that can educate, inform and will lead to an improvement in the quality and care provided in health and social care.

### **Q. Do you feel that the draft standards will drive improvements in national health and social care data collections to support data quality?**

Please comment:

The availability of up to date comprehensive data clearly has considerable potential for disease monitoring and health and social care services management and related outcomes.

Ideally, there is a need for more focus on collecting the data in a manner that enhances matching and interoperability. This would probably require the inclusion of an additional Standard and related Features, probably under Theme 3, 'Use of Information'.

## 3. Specific feedback questions

- Can these draft standards and features be applied to the national health and social care data collections in a manner that supports good information governance and management?
- In your opinion are the standards and the features that follow each standard clear and easy to understand?

### **Theme 1: Person-centred**

#### **Standard 1 — Person-centred**

As stated above, the term 'person-centred' as a Theme may need to be looked at again in terms of what it means in the context of Data Collections which by their very nature are systems-focused.

A key principle of using personal health and social care information referenced is that the data subject is aware of how their data is being used and of their right to opt out. This poses major challenges in respect of people with cognitive impairment and reduced decision-making capacity.

Feature 1.5 states that “where consent is required an appropriate structure is in place to ensure that consent has been obtained in accordance with legislation, standards and best available practice”. This needs to be spelled out in accordance with the provisions of the Assisted Decision- Making (Capacity) Act 2015, viz.

- Regarding every individual as having capacity until proven otherwise and always seeking consent from an individual in the first instance
- Adhering to the principles set out in Section 8(10) in respect of the sharing of information
- Implementing the concept of supported decision-making.

## **Theme 2: Leadership, governance and management**

### **Standard 2 — Governance arrangements**

The development of a separate guidance document referenced in the Draft Standards will be particularly important in this regard.

It is not clear what the formalised agreements with data providers referred to in 2.4 would entail - implementing such agreements in practice by management organisations would be likely to present significant challenges.

### **Standard 3 — Statement of purpose**

The need for a clear statement of purpose is referenced in a general way. However, what is not clear is how the generic term 'health and social care' is to be understood and interpreted and what type of data is to be included. This is particularly relevant in the case of some people, e.g., older people with support needs and people with disabilities, where the most important quality of life and health component may be supports for independent living where outcomes are not easily measured.

### **Standard 4 — Legislation**

There should be specific reference in this Standard to relevant legislation and some Features included relating to compliance with the following pieces of legislation.

- The Data Protection Act 1988 and the Data Protection (Amendment) Act 2003
- The Mental Health Act 2001
- Health Identifiers Act 2014
- The Assisted Decision Making (Capacity) Act 2015
- The Health Information and Safety Bill 2015 (when enacted).

## **Theme 3: Use of information**

### **Standard 5 — Compliance with national standards**

- It would be helpful to get managing organisations to disaggregate data on the basis of (a) self-reporting by users of health and social care services (b) process data inputted by administrators/managers and (c) observational data inputted by health and social care professionals;
- It would be useful to include a Feature here on 'Clarity of Purpose' in relation to why data is being collected
- Provision should be made for how both paper and electronic information exchanges between managing organisations are to be managed and additional Features included accordingly.

## **Standard 6 — Data Quality**

It is of crucial importance that data collected can be mined and interrogated in a resource efficient manner - ideally, this requires data collection design templates which might be developed in due course by HIQA and compliance assessed on how effectively these templates were being implemented.

Given the potentially valuable contribution of qualitative data, some specific reference should be made to the collection and management of such data and some additional features included under this Standard.

## **Standard 7 — Accessibility of information**

It is not clear who is responsible for developing the Data Dictionary referred to in 7.2 - is this envisaged as being done at national level and, if so, who will be responsible for so doing? Also, there needs to be a requirement that qualitative data is presented in a manner that is robust, coherent and comprehensible.

## **Standard 8 — Dissemination of information**

This Standard suggests a need for compliance with some overall quality national template or mechanism in order to ensure that data is presented and disseminated in a manner that optimises usage.

## **Theme 4: Information governance**

### **Standard 9 — Information governance**

Best data collection practice requires that data held by a range of health and social care providers is integrated, This requires a strong focus on interoperability referred to above. However, data sharing between organisations raises the question of how accountability to the person who provided the data in the first instance is to be maintained.

The Features included in Standard 9, are, therefore, centrally important and monitoring compliance may be somewhat difficult in practice.

It is likely that in many instances, there will be two types of workforce involved and this needs to be acknowledged (a) staff whose primary role is data collection and analysis and (b) staff for whom data collection is ancillary to their main role.

Different types of training will be required for the different levels of engagement with the data collection process.

## **Theme 5: Workforce**

### **Standard 10 — Workforce**

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## **Theme 6: Use of resources**

### **Standard 11 — Use of resources**

The effective use of resources can only be adequately assessed in the context of outcomes. This question needs to be considered in the context of the statement of purpose (Standard 3) and the need to have identifiable targets and measurable outcomes.

**Are there any other general comments you would like to make? Please feel free to use additional space or continue on a separate page.**

The effectiveness of the Draft Information Management standards for national health and social care data collections will evidently be largely determined by the level of implementation which in return will relate, to some extent at least, to the nature and consistency of monitoring.

The challenge of implementing the standards across the board is all the more complex because of the range of data management organisations involved and the different styles of reporting already in existence. Optimising the interrogation and usage of the data would be enhanced by the availability of some structure or body at national level for oversight and integration. This would be different to standards monitoring in that its role would be to look generally at comparative potential, interoperability and related data gaps. Also, any such body would have an overview of the respective contributions of health data and social care data in examining the overall health, quality of life and well-being of different segments of the population. For example, information collected in a needs assessment under the Disability Act 2005 is likely to include a range of information about a child's socio-economic circumstances which would be very relevant in informing the overall management of disability.

The point made at the beginning of the Draft Standards document, that it is essential that all staff members within each national health and social care data collection understand and adhere to the standards in order to ensure compliance at every level, is a critical one. This can be related to the need for absolute clarity of purpose and related accountability by managing organisations.

The Draft Standards provide a potentially valuable stimulus for using data sets in a more integrated and developmental manner and when fully operational should certainly help to optimise the generation and use of health and social care data. The enactment of the Health Information and Safety Bill 2015 will obviously also be a crucial factor.