Citizens **Information** Board
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HIQA Draft National Standard Demographic Dataset and Guidance

A Submission by the Citizens Information Board

The Citizens Information Board (CIB) welcomes the opportunity to comment on the National Demographic Dataset and Guidance for use in health and social care settings in Ireland.

The Board believes that such a dataset should enhance access to health and social care services and better ensure the provision of the appropriate health care to each individual. It would also help to minimise duplication and related wastage in the system. While such a dataset will potentially be valuable, it is important to bear in mind that the dataset alone cannot deal with all the problems of communication between the various elements of the health service.

Issues of access to health records and of communication between providers of health and social care services are frequently reported by users of services provided by CIB delivery partners.[1] The most frequent problem reported is lack of communication between GPs and community care personnel and hospitals and community care personnel. There are also particular problems reported relating to access to health records when changing doctors or moving from one part of the country to another.

The use of a Unique Health Identifier system as envisaged in the Demographic Dataset has the potential to provide more effective linkages between the primary and secondary health care domains and between the public and private sectors irrespective of the locations of service. It should also eliminate the need for people using health and social care services to provide personal details at every contact with the system which is unnecessarily time consuming. The Dataset should also serve to eliminate duplication of information arising from repeat contacts by the same individual with primary and secondary care services and, thereby, facilitate better service and care planning for individuals and more effective integration between primary and secondary care and between health and social care.

The fact that the proposed dataset would not contain substantive health data about an individual and would be separate from records holding more detailed

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[1] The CIB has four service delivery partner networks: Citizens Information Services (CIS); the Citizens Information Phone Service (CIPS); the National Advocacy Service (NAS) and the Money Advice and Budgeting Service (MABS).

personal health information is, in the view of the CIB, a primary consideration given the understandable concern about individual privacy and protecting confidentiality. There are particular difficulties associated with collecting data from people with reduced capacity and in ensuring their privacy.

The CIB suggests that the Dataset could be enhanced by the following provisions:

- A clear statement that this Dataset is a first step in developing a more integrated National Health Demographic Dataset (e.g. Electronic Health Records).
- Clarity about the purpose and the limitations of the Dataset and the Unique Identifier and who will have access to the information on the Dataset
- Clear information about the electronic nature of the dataset
- Individuals being informed that the information provided will be available to other health and social care agencies
- The issuing of a ‘card’ to each individual carrying his/her Unique Identifier Number
- A clear explanation of the fact that there will be complete separation between the Unique Identifier Dataset and personal health records
- Stringent safeguards to protect the personal health information of every individual and to ensure that the Unique Identifier can only be used for the purposes for which it is intended
- Protocols which ensure protection against the inadvertent linkage of information on the Dataset with other personal health and clinical information
- A clear explanation of if and how the unique identifier dataset would be used to trigger access to individual clinical records

The use of the Dataset to trigger access to medical history and records would have to be strictly limited to those entitled to legitimately and professionally access such information. This is likely to raise particular difficulties in settings which provide social care (as distinct from medical care) primarily. It may also present difficulties in cases where a person has communication difficulties or lacks full capacity (e.g., as in the case of some people with an intellectual disability).

Other Information to be Included in the Dataset (Consultation Question 2)

Consideration should be given to including the following pieces of additional information on the dataset:

- Nationality
- Details of contact person in an emergency
- Inclusion of any specific information centrally relevant to his/her health care that person wishes to provide
- If the person requires assistance with communication

Linkages with Broader Dataset Systems

Unique Identifiers for Healthcare Practitioners and Organisations

The CIB notes that HIQA has also recommended the introduction of unique identifiers for healthcare practitioners and organisations which would identify the issuer of the subject of care identification. Clearly, there are a number of potential practitioners and organisations who could be included – hospitals, general practitioners, primary care centres, residential centres for older people, children's residential centres and allied health professionals. There is a need to indicate when this initiative is likely to be implemented and what are its implications for implementing the 'subject of care' identifier.

Other Proposed Unique Identifiers

A general question arises as to how the proposed dataset relates to the the development of a system of unique identification for the health service referred to in *Towards 2016* in the context of a public service wide approach to the development and use of unique identifiers. It is noted that the Department of Finance is currently considering the development of a public service wide system for identity management purposes which is concerned primarily with how public sector agencies identify people, how agencies can establish basic facts about people with whom they are dealing, and how people can prove their identity when accessing services remotely. It would seem logical that a scheme of unique identification for the health services should build on and be consistent with any proposals that might emerge from this and any other government initiatives.

Electronic Health Record

Another important question is how the proposed Dataset will link with the Electronic Health Record (EHR)[2] initiative which is being developed internationally in the context of e-health systems and which is also being explored in Ireland. International experience with the development of national EHRs reported by HIQA[3] highlights the complexity and challenges involved. The consensus internationally recommends an incremental step-by-step implementation strategy based around supporting a standards-based approach to exchanging medical and health information which will allow more information to be made available electronically including, for example, patient identification, medication, referrals, and discharges.

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[2] An EHR is an electronic version of a patient's medical history that is maintained by the healthcare provider over time and may include all of the key information relevant to that person's care.

[3] See HIQA (2011), Developing National eHealth Interoperability Standards for Ireland: A Consultation Document.

The CIB notes that HIQA is working with stakeholders to define a prioritised list of areas for the development of eHealth Interoperability Standards and is working towards establishing a clear roadmap for the development of these standards which will ensure the key building blocks for the introduction of a national EHR at some time in the future. The CIB also notes that the HSE has issued a tender for a four-year national integrated services IT project using electronic health records to underpin its integrated service delivery plan.

Implementing the Dataset

The CIB identifies four factors that need to be taken into account in implementing the Dataset.

Confidentiality

The particular difficulties related to ensuring that confidentiality is protected in an electronic dataset (even the most minimum as currently proposed) need to be openly acknowledged, particularly where information provided in one setting (e.g. hospital) is to be transferred to another setting (e.g. a private nursing home). It is noted that information provided to a health professional (which an individual agrees to provide on the basis of confidentiality) may be different from the type of information that an individual may wish to provide in another setting.

Ethos of Data Collection

While the development and maintenance of datasets is not an end in itself, it is a key component in planning and delivering a quality service. There is a need to foster a stronger ethos of standardised data collection with a clear rationale and purpose throughout the system. This is vital if the necessary time, resources and back-up support are to be allocated to the task.

Data Retrieval

It is important that the dataset is designed in such a way that the data is easily retrievable. Capacity to retrieve the data should be an integral part of the system.

Resource Implications

There are significant resource implications in developing and maintaining a standardised dataset for health and social care services. Care is thus required in order to ensure that service to individuals is not lessened because of data collection requirements.

Mandatory or Optional

A question to be addressed is whether participation in the system should be mandatory. This would mean that a Unique Identifier Number would be issued to all persons who receive health and social care services in the State. Given that it is unlikely that any individual would be refused care if s/he did not provide the information required for the Dataset, there is a question as to how such situations are to be dealt with in order to provide for a fully inclusive Dataset in the longer term.

Ensuring Participation by Relevant Agencies and Practitioners

Unless there is full support for the Unique Identifier Dataset by the population in general, by health practitioners and relevant health and social care agencies, the benefits of the Dataset will not be realised. Furthermore, the system would be at risk of becoming dysfunctional in terms of its main purpose.

Questions Relating to Implementing the Dataset

The CIB identifies the following as key questions to be addressed in progressing the implementation of the Dataset:

(i) Who can issue a ‘subject of care’ identifier?

(ii) Who is to develop, operate and monitor the dataset?

(iii) How will the Dataset be accessed?

(iv) Are there training implications and, if so, how will these be catered for?

(v) Will individuals be able to access their own record on the Dataset?

(vi) Who will decide which health /social care professionals will have access to an individual’s record?

(vii) Who will be responsible for putting in place the required IT systems and interfaces and other security protocols?

(viii) What costs are associated with setting up and maintaining the Dataset and how will these be met?

(ix) What are the next steps?

(x) When are the other elements of the Dataset to be implemented (unique identifiers for practitioners and agencies)?

(xi) What protocols will be put in place to ensure that the unique ‘subject of care’ identifier cannot be linked inappropriately with other datasets.

(xii) What will be the processes for reviewing the system?

Overview

The CIB agrees that the proposed Dataset is a significant stepping-stone in a move towards a more integrated and accessible health care records system. However, the Board is of the view that the introduction of the Dataset must be based on clarity of purpose and clarity of roles and responsibilities.

The CIB takes the view that the dataset should not commence until other parts of the infrastructure are in place, including, in particular, a listing of the health and social care practitioners and organisations that can make inputs to the Dataset. This latter listing is important even if the relevant unique identifier system for agencies and practitioners is not in place. Ideally, the introduction of unique health identifiers for health care practitioners and for health and social care organisations should be introduced at the same time as the ‘subject of care’ identifier for individuals.

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

Finally, and very importantly, the CIB notes the somewhat technical nature of the Dataset protocols as set out in the Guidance 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.