**Draft Recommendations on a Model for Health Information Standards to support the delivery of health and social care services in Ireland: CIB Submission in Word**

Question 3: Model for health information standards and governance structures to support it (Recommendations 1.1-1.9)

CIB supports the creation in the medium-term of a new strategic independent entity to set and implement health and social care information standards. The operation of this independent entity would be very much informed by the strong track record of HIQA in developing standards and implementing regulations in the residential care sector and monitoring compliance with National Standards for Safer Better Healthcare.

The Model for Health Information Standards will need to be fully aligned with the wider transformation of health service delivery and with longer term priorities under Sláintecare, for example, with the national eHealth solutions programme, including the National Shared Care Record, as those programmes evolve.

The components of a standards setting function set out in 1.3 are all relevant in developing the Model as is the identified requirement for legislation to mandate compliance with the standards.
It is clear that standards without a mandatory compliance system would fall far short of what is required to deliver an integrated information system for all health and social care services.

The Model will need to include provision for the management of the significant changes required within and across health and social care agencies in order to comply with health information standards. This will be particularly important in the context of an evolving and changing health and social care system with a growing reliance on private providers.

The Health Information Standards Model must take full account of the fact that effective information sharing is an integral aspect of the multi-agency and multi-disciplinary approach required to provide adequate health and social care. The importance of sharing information and of being able to rely on a legal basis to do so is of paramount importance.

The development of the Model will need to take into account the obvious training implications relating to implementing health information standards.

Question 4: Standards development process (Recommendations 2.1-2.8)
The Standards development process will need to include the following components:

* Provision of clear protocols for ensuring that a person-centric approach is reflected in the health information standards;
* Ensuring that the challenges associated with the ICT enablement and capacity-building required to implement health information standards occurs across all health and social care settings are addressed;
* Identification of the resource implications of the model taking into account the fact that health and social care providers (hospitals, community care and residential care) will require a change management process and appropriately trained personnel to oversee its implementation;
* A clear statement will need to be developed about the health and social care providers to which the health information standards will apply;
* The development of the Model will need to take account of:

	+ How to bring together information from various systems into a single platform for use by health and social care professionals in the delivery of care;
	+ How to involve end-users of the system, including, in particular, the ‘data subjects’ (users of health and social care services)
* The standards development process will need to be based on a clear vision for the short, medium and long term. This vision should be developed in collaboration with all stakeholders in order to develop a common and agreed understanding of what the standards will entail across the full health and social care sector, public and private.
* In developing the standards, provision will need to be made for linking the standards with national eHealth solutions such as the National Shared Care Record, as these evolve.
* A Roadmap should be identified which sets out how the Model for Health Information Standards is to be developed incrementally taking into account the need for a standardised and standards-based approach to sharing health and social care information relating to patient identification, medical history, medication, referrals, discharges and assessed health and social care needs.
* The roadmap will need to set out how mechanisms are to be developed for enabling all health and social care providers to use a national standardised electronic information system.
* The Roadmap will need to identify how the significant funding, specialised skillsets and training are to be provided and how the resource implications will be addressed.
* The Roadmap will need to take into account the challenges posed by the current health and social care delivery model, in particular, the current two-tier system of long-term care and the significant (and increasing) role of the private sector in the provision of acute hospital care, residential care and community-based care.
* The question of what costs will be associated with developing, testing and implementing the Standards will need to be addressed at development stage.

# Question 5: Stakeholder Engagement (Recommendations 3.1-3.7)

It will be essential that all stakeholders who will have responsibility for implementing Health Information Standards are fully on board and have a common understanding of what the Standards will entail.

Unless there is full support for a health information standards model by the population in general, by health and social care practitioners and relevant health and social care agencies, the benefits of having national health information standards will not be realised.

The engagement of the different stakeholders in shaping the model, for example, acute hospitals, nursing homes, GPs, consultants, and community care services, will be central to achieving buy-in to a best practice approach based on the concepts of inter-operability and shared digital platforms.

It will be vitally important that the Model is informed by subject matter experts (both clinical and technical) as well as by public (citizen) interest groups. The experience to date of HIQA in developing standards will be highly relevant. It will also be important to include experts in data sharing who have a detailed understanding of GDPR requirements and existing data protection legislation.

Stakeholder engagement should include disability organisations and migrant and ethnic groups.

There are a number of specific factors that need to inform stakeholder engagement in the standards development process:

* How to ensure that the Health Information Standards Model will deal with settings which primarily provide social care (as distinct from medical care), in settings involving less-well trained staff, and settings managed by private contractors.
* The development process will also need to make provision for engaging end users of health and social care services and include provision for ‘public interest’ stakeholders to be involved.
* How to engage citizen stakeholders who lack decision-making capacity (e.g., as in the case of some people with an intellectual disability, with dementia, or some people experiencing mental health difficulties) will need to be explored, particularly in the light of the Assisted Decision-making (Capacity Act 2015 which is scheduled to be commenced shortly.

# Question 6: General Comments

The obvious value of having an Integrated IT Information 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.

While most users of health and social care services will be aware that information about them needs to be shared among the healthcare professionals delivering care, they should be informed that they have a right to ask for certain information to be withheld or kept confidential.

The Information Standards Model will need to ensure that any sharing of information, such as between the HSE and other health and social care providers in the private and the voluntary sectors meets all data protection and regulatory requirements. A key question to be addressed is the extent to which non-HSE funded services will be required to comply with regulatory standards, particularly in the context of data sharing.

There is a need to fully recognise that a significant proportion of staff, especially in the home care and nursing home sectors are – at present – poorly trained and equally poorly remunerated. Many do not enjoy or have access to the supports and conditions that are more prevalent in the HSE and state sectors. The development of new health information standards will, therefore, need to assess and plan for how the information management requirements will impact on them.

CIB suggests that in developing the Model for Health Information Standards, the following considerations should be included at the beginning and throughout the process:

* A clear statement that health information standards are integral to the development of a seamless health and social care service;
* Clarity about which health and social care staff (and under what conditions) will have access to the information held on various systems and platforms;
* How to provide for fully informing individuals who use health and social care services that any information that they provide in one health or social care setting will be available to other health and social care agencies and their staff;
* How to manage security concerns in order to avoid the potentially significant fallout if the system was to be subjected to a cyber-attack.

#### Consent to use of personal health informationThe maintenance and retention of health and social care records and their use for research in the cases of people who are not in a position to give consent is a matter which requires more detailed consideration as the Health Information Standards are being developed. The provisions of the Assisted Decision-making (Capacity) Act 2015 for supported decision-making are centrally important in this regard.

Confidentiality
The Health Information Standards will need to cater for particular challenges related to user/patient confidentiality. This is particularly relevant where personal health information provided in one setting (e.g., hospital) is to be transferred to another setting, e.g., a private nursing home or a private home care provider. Information provided to a health professional on the basis of confidentiality, e.g., to a GP, may be different from the type of information that the individual may wish to provide in another setting, e.g., to a home care provider.

There is strong anecdotal evidence that personal information regarding patients/health and social care service users has in the past been made available to ‘next-of-kin’ and other family members without the knowledge or express permission of the person concerned. The proposed health information standards will need to ensure and make clear that such data sharing is not acceptable or possible.

While e-health and electronic health records should mean greater efficiency in the delivery of health and social care, the Health Information Standards must be such as to anticipate and address problems relating to security, privacy and confidentiality associated with digital systems. Particular care needs to be taken to ensure that personal data are only used for the purposes for which they were created. This is already a requirement under the data protection legislation.

*Standardised data collection*There is a clear need to foster a strong ethos of standardised information collection throughout the whole of the health and social care system (public and private).

*Retrieval of information*Capacity to access and retrieve the information must be an integral part of any new health information system.

*Resource implications*

There will be significant resource implications in implementing health information standards across the very wide range of health and social care services.

CIB agrees that the development of health information standards would be a significant move towards a more integrated and accessible health and social care system and centrally relevant to the implementation of Sláintecare. The introduction of health information standards must, however, be managed incrementally in a manner that ensures that each phase of the process is consolidated before moving on to the next phase. Engaging all stakeholders (agencies and practitioners) at each stage of the process and getting inputs at each stage of development from potential users of the system will be essential.

Pending the establishment of a new agency (an independent entity with full responsibility for the delivery of Ireland’s national health information system), there is a need for clarity in the interim about the respective roles of the different agencies – HIQA, the HSE and the Department of Health – in developing health information standards with particular reference to which agency has overall leadership responsibility. There is also a need for clarity about which parts of the system will be managed nationally and which will require management at regional/local level.

While the introduction health information standards will be an important step forward in implementing an integrated health and social care system, clearly, the Standards must be introduced in tandem with the passing and commencement of proposed legislation on the development of a national health information system. CIB considers that the proposed legislation should be accompanied by education and training measures to ensure that the systems that are put in place to facilitate information management and sharing do not become substitutes for a genuine culture of communication.

The proposed legislation and the Health Information Standards, as well as dealing with information about patients/health and social care service users, should also deal with information for users and potential users of health and social care services. Relevant information would include the level and quality of services available from the various health and social care providers, the range of treatments available, the qualifications of health and social care staff, the staffing ratio of hospitals and other health and social care providers and similar information. This would enable patients and social care service users to make informed choices about their health and social care. Access to such information is especially important as more services are being provided by the private sector.