

# Response to the discussion paper on proposed Health Information Bill

11 Sep 2008

The Institute of Public Health in Ireland is an all-island body which aims to improve health in Ireland by working to combat health inequalities and influence public policies in favour of health. The Institute promotes North-South co-operation in research, training, information and policy. The Institute commends the Department of Health and Children for producing the *Discussion Paper on Proposed Health Information Bill (June 2008)* and welcomes the opportunity to comment on it.

## 1. SUMMARY

The first objective of the *Health Information: A National Strategy (2004)* is to support the implementation of *Quality and Fairness: A Health System for You (2001)*. The National Health Goals - such as 'Better health for everyone', 'Fair access' and 'Responsive and appropriate care delivery' - are expressed in terms of the health of the public as well as patients.

The Discussion Paper focuses on personal information, and the data flows within the health system, that are needed to enhance medical care and maximise patient safety. The Institute believes that the Health Information Bill should also aim to more fully support the achievement of the National Health Goals and the public health function. This requires the development of more integrated information systems that link the healthcare sector and other sectors.

Assessment of health services performance - in terms of the public's health, health inequalities and achievement of the National Health Goals - require such information systems. They will enable the construction of public health key performance indicators for the healthcare services.

The Institute suggests that to achieve this, the Health Information Bill would need to extend its focus by:

- Considering a wider range of information
- Facilitating other relevant uses of information
- Enabling wider data flows
- Supporting appropriate structures and processes

## 1.1 CONSIDERING A WIDER RANGE OF INFORMATION

Efforts to improve the public's health and reduce inequalities require a multi-sectoral approach. Effective public health action needs to be based on information from the health and social services (including personal healthcare information), other government departments, the community and voluntary sector, private enterprise and the general public. This information is essential to support efforts to move towards greater use of community-based care.

## 1.2 FACILITATING OTHER RELEVANT USES OF INFORMATION

Personal patient information is needed in several forms to support the public health function:

- Personal information (infectious disease outbreaks, food safety and hygiene, environmental hazards, etc)
- Detailed aggregated information for comparison to population counts in order to assess equity of access to healthcare as well as examining population patterns and trends in morbidity and mortality
- Linked to other data outside of medical care such as population survey data, longitudinal studies for research and analysis purposes.

## 1.3 ENABLING WIDER DATA FLOWS

The Discussion Paper highlights data flows of personal information within the “circle of care” inside the health system. The Health Information Bill should also provide a legislative framework to support data flows involving other sectors. Of particular importance to both medical care and public health, is the inclusion of the private healthcare sector.

## 1.4 SUPPORTING APPROPRIATE STRUCTURES AND PROCESSES

The development of more integrated information systems that build bridges between the “islands of information” that currently exist would be further facilitated by

- The development and support of inclusive, transparent and accountable management of the national health-related information systems.
- The development and implementation of information standards.

Further details about these four points are given in Section 2.

## 2. FURTHER DETAILS

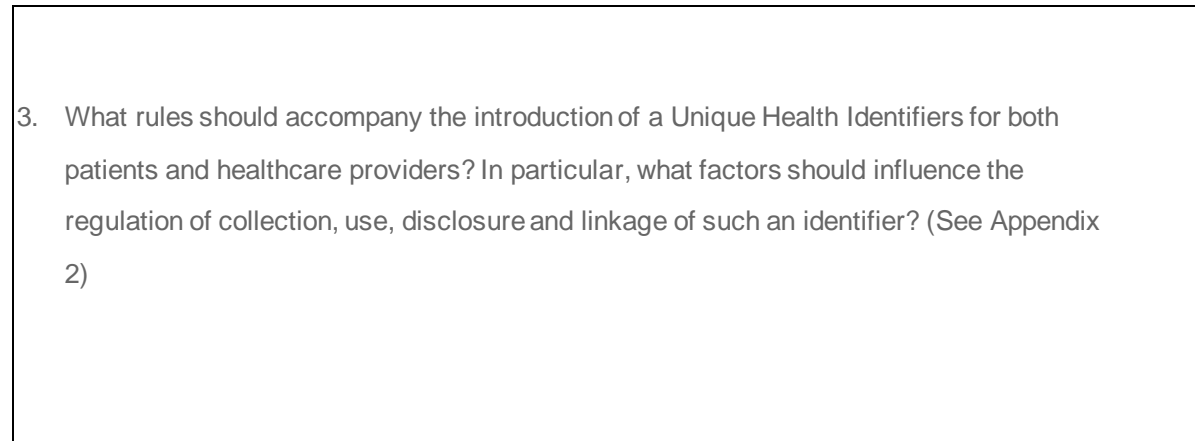
1. What are the benefits to patient care and safety which should be the objectives of any legislation? (See Part 1)

- The Institute believes that the proposed Health Information Bill affords a real opportunity to strengthen the currently inadequate information and intelligence support for public health function and cross-government efforts to achieve its National Health Goals.
- The Discussion Paper should extend its focus on the National Health Goals and the public health function. It should also properly consider the public health benefits that could be realised from taking a broader approach to the use of personal health information. Amongst the potential public health benefits are contributions to:
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  - Health needs assessments including a better understanding of patterns of disease and disability, and the identification of populations at risk and other emerging health issues and
  - Monitoring and surveillance of disease and disability, and their determinants and consequences
  - Monitoring the performance, and value for money, of the healthcare system
  - Development, delivery and evaluation of public health interventions to improve health and reduce health inequalities.

2. What is the balance to be struck between the rights of individuals to control their healthcare information and the needs of those managing healthcare systems, providing health care services and undertaking medical research (including the role of Research Ethics Committees) to have limited and controlled access, without individual consent, to such information for legitimate purposes? (See Parts 2 and 3)



- The use of personal health information serves both a private good and a public good.
- The suggestion that more weight should be placed on the National Health Goals and public health benefits reflects a belief that it is possible to place a greater emphasis on population-level information needs at the same time as respecting individual rights to control personal healthcare information.
- In order to achieve that balance, the Health Information Bill should provide a legislative framework for the structures and processes – covering the collection, sharing, disclosure, transfer and use of information - that need to be put in place.
- Some formal consideration should be given to how that balance could be achieved. One principle might be to ‘provide the least necessary access to health information that will provide the most benefit to the most people’.
- International and local experience suggests that these structures and processes need to be inclusive, transparent and accountable. They should use a consensual approach that balances public good against private rights and is based on shared and agreed values.



3. What rules should accompany the introduction of a Unique Health Identifiers for both patients and healthcare providers? In particular, what factors should influence the regulation of collection, use, disclosure and linkage of such an identifier? (See Appendix 2)

- In order to support better medical care and patient safety, the UHI needs to be available to both public and private healthcare providers.
- Particular consideration should be given to minimising the risk that linked health data might prejudice a person’s health insurance options.
- There are considerable population-level benefits to using the UHI to link personal health information to other population-based information from other sectors. For example, the national longitudinal studies (based on linking a sample of Census records in Northern Ireland and parts of Britain) have made very valuable contributions to understanding the determinations of public health and health inequalities.

- It seems sensible to assign a UHI at birth.

4. What legal issues need to be considered in establishing a National Electronic Health Records system: especially as regards an individual's choice to participate or not and his or her control over the extent of any participation? (See Appendix 1)

- An EHR system would greatly improve healthcare and the public's health. The Institute supports the development of an EHR for Ireland.
- A key legal issue is whether participation will be mandatory, opt-in or a combination of both. In some areas of public health such as notifiable conditions, participation is mandatory. Generally speaking, provided necessary safeguards are put in place and the purpose of collecting the information is fully explained to individuals and the general public, mandatory provision of a minimum dataset is usually the best way to achieve the necessary coverage and data quality.

5. What principles should guide the development and regulation of National Population Health Registers, such as the National Cancer Registry, and the instances in which reporting to such registers should be mandatory? (See Appendix 3)

- Population Health Registers serve a range of patient and public interests. They play key roles in facilitating medical and community care, supporting patient safety, and developing and delivering healthcare services. They also play key roles in clinical and population-based epidemiological research, and monitoring and surveillance of disease patterns.
- Over time, Population Health Registers will become key information systems to help deal with the growing burden of chronic diseases such as diabetes to the healthcare system and the community.

- Population Health Registers should be based on consistent legal and ethical positions - on privacy, confidentiality, security, integrity, and consent – that recognise the need to link their data to other relevant sources.

6. What needs to be done to provide consistency and clarity in and between legislation, other legal rules and professional ethical codes in the treatment of personal health information having regards to considerations of privacy, confidentiality, consent and security? (See Parts 2 and 3)

- Privacy, confidentiality, consent and security are not guarantees against the misuse of health information. Another important aspect for providing consistency and clarity in the treatment of personal health information would be to have structures and processes that are inclusive – involving patients, the public, healthcare staff, service managers, researchers, etc – transparent and accountable
- If health information is to be used to the maximum benefit of the population and to improve public health, it is important to minimise harm to the individual(s) and communicate potential benefits to both individual patients and the wider population.

7. Is there a need for a comprehensive definition of personal health information and if so, what should it encompass? (See Parts 2 and 3)

- It would be useful if the Health Information Bill included a broad definition of the “health system” that recognised the role of other sectors
- It would be useful if the Health Information Bill applied to broader health and social care which includes medical care.
- The inclusion of the private health care sector is essential for managing patient flows across the public-private interface and its impact on medical care and patient safety. Without the private healthcare sector, many of the uses of health care utilisation information and the measurement of morbidity at population-level will remain limited.

- It would be useful if the Health Information Bill included a comprehensive definition of the health information that is needed to support the National Health Goals including the public health function as well as patient safety and the quality of medical care.
- The national health information strategy emphasises the need to disaggregate health information in order to identify patients from particular population subgroups and to deliver appropriate healthcare. Personal information should enable it to be disaggregated using demographic and socio-economic details and the nine equality grounds (gender, age, marital status, family status, disability, race, sexual orientation, religious belief and membership of the Traveller Community).
- Contextual information such patient's living and working condition is particularly important in rehabilitation services.

8. To what extent do certain categories of personal health information – for example, mental health information and information on children and diseased individuals - require special rules on collecting, keeping, using, disclosing and accessing? ( See Parts 2 and 3)

Some categories of personal information – such as income - are considered 'sensitive' by large percentages of the general public. Other categories of personal information identify subgroups of the population that are particularly vulnerable – eg persons with mental health disorders, children, etc. Many of these data items are necessary to develop and deliver programmes to help achieve National Health Goals and monitor their performance.

- It is therefore important to have special rules for such categories of health information to ensure high standards of protection.
- Healthcare workers and administrative staff often collect this information and require guidance on how to gather it in a respectful manner. There is clear evidence that, without this guidance, staff tend to over-estimate sensitivities and lack skill to deal with existing sensitivities. This undermines the coverage and accuracy of the information and limits its utility.
- The best approach would be to have inclusive, transparent and accountable processes - involving patients, their guardians/next-of-kin, healthcare staff - to develop such guidance, evaluate its implementation, and review it on a regular basis.

9. Should the Health Information Bill be a comprehensive piece of legislation dealing with all the relevant issues or should it build on the legislative framework (data protection and freedom of information) that is already there and working well? (See Part 1)

- By including the development of a legislative and information governance framework as one of its objectives, the national health information strategy recognised the special information needs of health and some of the limitations of the existing legislative framework.
- The national health information strategy noted, for example, that the legal basis for EHR and UHI could not be provided by existing legal framework. The Discussion Paper noted several other gaps, inconsistencies and ambiguities in the interpretation of the existing acts.
- These inadequacies need to be addressed in the Health Information Bill, and some coherence between its underpinning principles and those of the existing acts is vital. In particular, the relationship between rights conferred by the Health Information Bill and rights conferred by both the Data Protection and Freedom of Information Acts will need to be clarified. Otherwise the new Bill could add further ambiguity.
- Some changes may be even needed to the existing legislation.
- There is clear evidence that healthcare staff, service managers and data holders require guidance on these issues.
- In identifying the way forward, the chief criteria should be the extent to which the various approaches either enable or hinder the achievement of the objectives of the Health Information Bill
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