



**IRISH HEART  
FOUNDATION**  
Fighting Heart Disease & Stroke

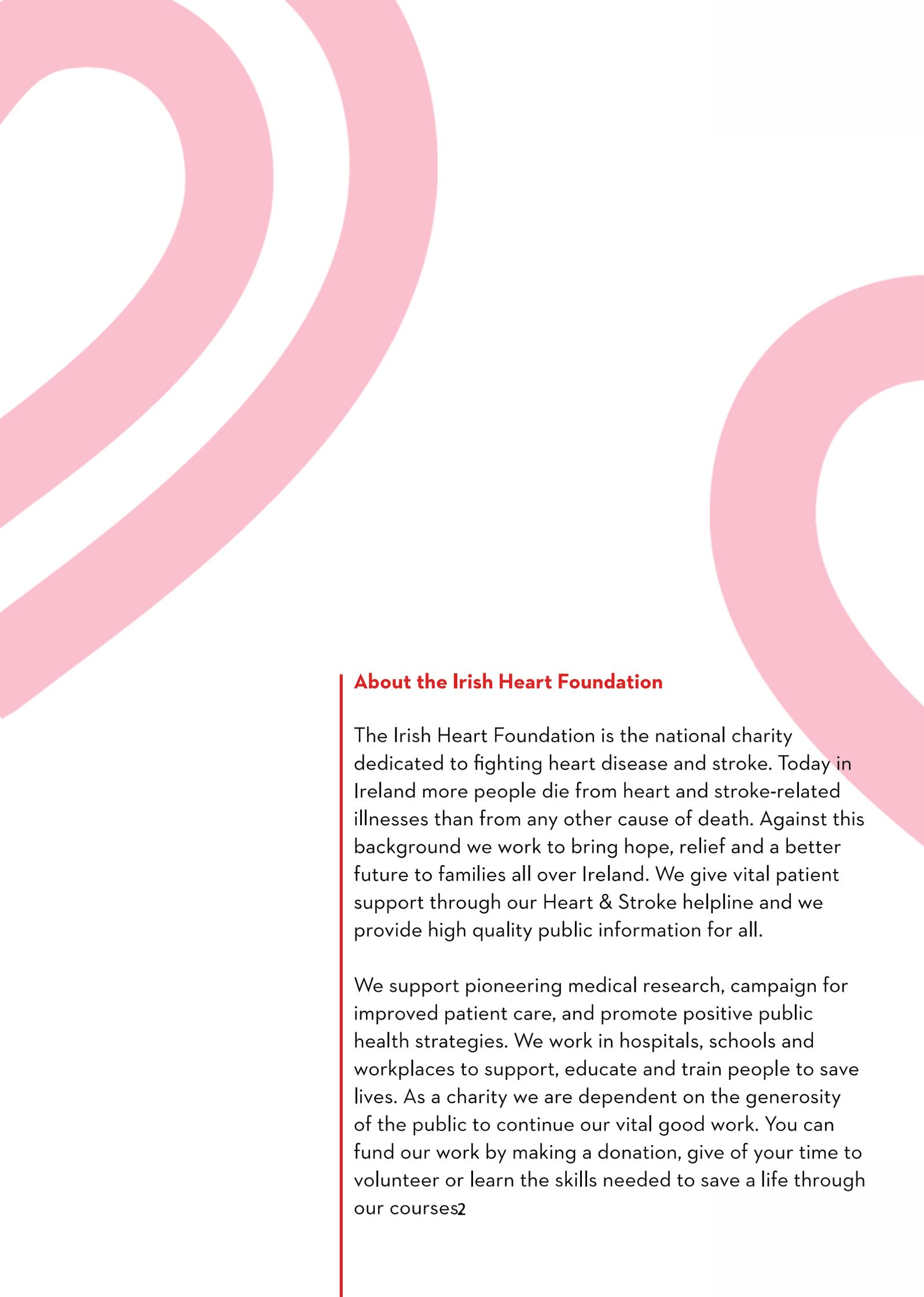
## **Irish Heart Foundation**

### **Submission**

Draft information governance &  
management standards for the  
health identifiers operator

April 2015





## About the Irish Heart Foundation

The Irish Heart Foundation is the national charity dedicated to fighting heart disease and stroke. Today in Ireland more people die from heart and stroke-related illnesses than from any other cause of death. Against this background we work to bring hope, relief and a better future to families all over Ireland. We give vital patient support through our Heart & Stroke helpline and we provide high quality public information for all.

We support pioneering medical research, campaign for improved patient care, and promote positive public health strategies. We work in hospitals, schools and workplaces to support, educate and train people to save lives. As a charity we are dependent on the generosity of the public to continue our vital good work. You can fund our work by making a donation, give of your time to volunteer or learn the skills needed to save a life through our courses<sup>2</sup>

# **SUBMISSION TO HIQA**

## **Draft information governance and management standards for the health identifiers operator**

**April 2015**

The Irish Heart Foundation (IHF) is the national charity supporting people with heart, stroke and blood vessel disease. The IHF promotes policy changes that reduce premature death and disability from cardiovascular disease and advocates for better patient treatment and services. We campaign for improved patient care, promote positive public health strategies and support pioneering medical research.

The IHF welcomes the opportunity to comment on the draft information governance and management standards for the health identifiers operator. The IHF has long supported the introduction of health identifiers, recognising their vital importance for all those using health services. Ireland continues to be an anomaly in the Western World in terms of the dearth of health data collection, the lack of interoperability between data sources and the lack of access afforded to the public to the health information stored about them.

In making this submission our primary aim is to welcome the ongoing work to develop health identifiers and to urge their speedy introduction. Health identifiers are a tool which should be used to improve the quality and effectiveness of the care patients receive in the short term, as well as a lever to implement longstanding policy commitments such as integration of health and social care services to provide seamless care; money-follows-the-patient financing across health and social care; and universal access to healthcare. In particular, health identifiers will support the development of shared care and chronic disease management programmes, where information on patient care is regularly communicated between primary and hospital settings. At the level of individual consultations, health identifiers should also take the unnecessary responsibility currently on patients to bring their own charts / test results to consultations.

There are considerable, ongoing risks to patient care resulting from the lack of patient identifiers, particularly incorrect identification of patients resulting in improper care. The IHF is also aware of the risks of health information systems for patients, particularly in terms of privacy and confidentiality and the necessity for a robust governance model to ensure that data is stored and used correctly.

## Questions posed in the consultation document

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In this section we respond to a number of the questions posed in the consultation document.

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

The IHF would welcome more detail on the controls which will be in place to ensure that data from the health identifier system will not be used for commercial gain. We welcome the restriction on the data available to health insurers in the system. Insurance companies should not have a proprietary control of health information.

The health and social care system comprises organisations of vastly different sizes and IT capabilities. Some organisations may have little experience of complex information systems. The IHF would welcome further detail on how smaller providers – more likely to be in the social care field – will put in place appropriate systems to protect patient data.

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

Page 24 of the consultation document details the benefits which would accrue to service users, general practices, hospital and social care providers. The document does not mention the benefits of the health identifiers system for citizens (beyond those accruing to citizens when they are patients), such as: reducing duplication within the health system (better use of resources, leading to quicker access); increased efficiency of the primarily tax funded health system; and publication of data on healthcare use, enabling greater transparency about vital public services.

The section detailing benefits for health and social care users should be expanded to include more effective services (such as, the use of effective information services to speed up referrals and reduce waiting times) and better access to the information held about them in health information resources. The scope and nature of the standards should be revisited to ensure that they can achieve these benefits for service users.

In many cases, what the majority of services require from all service developments – including those relating to health information – is shorter waiting times in access to services / care. The role of the health identifiers in achieving shorter waiting times (such as by improving data transfer between health and social care providers, reducing lengthy referral periods) should be included as one of the criteria in the standards.

#### *Patient / service user involvement in the work of the health identifiers operators*

The IHF believes that the needs and motivations of service users should be more broadly reflected in the development of the health identifiers system. The advisory group for the draft standards contained only one representative of a patient advocacy organisation. HIQA and the Department of Health should seek to include a wider representation of patients in the governance structure as it develops.

#### *Secondary use of data*

There is limited detail in the standards on the secondary use of data for research, audit and patient registries.

### *Development of cardiovascular disease registry*

Health information is increasingly viewed as essential to plan health services. However, this is only possible when information is collected about a certain healthcare condition / treatment, such as the National Cancer Registry, but not in relation to other conditions (such as cardiovascular disease, which does not have a national registry). The limited nature of current information sources must be recognised in all service and policy planning mechanisms. The planning of services based on the health information which is currently collected could lead to a favouring of certain conditions over others. The mismatch which exists between the limited information that is available and the information which is required for service and policy planning purposes should provide an impetus for the development of additional health information resources. As the national charity representing patients with cardiovascular diseases (CVD), we are deeply concerned about the failure to implement a national CVD registry. This absence continues despite the fact that CVD is the most common cause of death in Ireland, accounting for 34% of all deaths and 20% of all premature deaths (before 65 years)<sup>1</sup>. CVD also results in extensive use of healthcare services – bed usage as a result of cardiovascular disease accounted for just over 685,000 bed days in 2008 (a 3.9% increase over 1998<sup>2</sup>).

In addition to the need to develop national registers for major diseases, the IHF believes there should be a commitment from the HSE to publish anonymised data drawn from the system on a regular basis detailing all elements of service provision. This would provide greater transparency about the operation of the health and social care services on an annual basis.

**Question 6: Having read the background information, do you feel that you understand the background to these draft standards? Is enough background information provided?**

**Question 7: 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?**

### *Sharing of information between health and social care*

For the individual needing care, the ongoing divide between the health and social care systems in terms of governance and funding is entirely artificial. The best patient outcomes will be achieved when there is good interface between the health and social care services. The introduction of health identifiers will enable easy transfer of patient information within the circle of care. Further information could be provided in the standards on how the health and social care systems will work together to develop shared communications systems.

### *Health service provider identifiers (HSPI)*

The IHF is unclear whether health service provider identifiers (HSPI) will be assigned both to organisations (e.g. hospital) and clinical staff working there (e.g. nurses)? Previous documents from HIQA referenced 'Healthcare practitioner identifier (HPI)<sup>3</sup> but this category appears to have been removed from the standards. The IHF believes that HSPIs at both setting and staff level would greatly benefit patient safety.

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<sup>1</sup> CSO. Vital statistics- Fourth Quarterly and yearly summary 2010 – Deaths from diseases of the circulatory system 2010

<sup>2</sup> Pg. 43, Government of Ireland. *Changing Cardiovascular Health – National Cardiovascular Health Policy 2010-9.*

<sup>3</sup> HIQA (2011) *Recommendations for Health Identifiers for Healthcare Practitioners and Organisations.*  
<http://www.hiqa.ie/publications/recommendations-unique-health-identifiers-healthcare-practitioners-and-organisations>

**Specific feedback questions on the standard statements and features that are presented under each theme.**

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

<b>Theme 1 Person-centred support</b>
<p>Person-centred support places service users at the centre of all that the health identifiers operator does. Person-centred support promotes consideration and respect for service users' dignity, privacy and autonomy.</p> <p>Being person-centred means that the health identifiers operator communicates in a manner that supports the development of a relationship based on trust. Good communication and the provision of adequate, appropriate information ensures that people using services and health service providers understand the role and purpose of health identifiers in the Irish health and social care system.</p> <p>Being person-centred also means that the health identifiers operator establishes and maintains the national registers in such as way as to protect service users and health service providers' personal information.</p> <p style="text-align: right;">(p.28, Consultation Document)</p>

Theme 1 is followed by two standards, emphasising the privacy and communications element of the theme:

- 1.1 The health identifiers operator conducts privacy impact assessments at critical points during the establishment and operation of the national registers.
- 1.2 The health identifiers operator develops, implements and reviews a communications plan that effectively informs service users in relation to the use of the national registers.

The IHF considers that a number of further standards should be considered to reflect other elements of theme 1, including:

- How service users will be placed at the centre of the work of the health identifiers operator's work – this standard could refer to ongoing engagement with service users through an advisory committee, or similar.
- A standard relating to maintaining the dignity of service users
- A standard on supports for service users to engage with the system and to bring complaints.

### **Conclusion**

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The IHF welcomes the opportunity to comment on the draft information governance and management standards for the health identifiers operator in Ireland

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**Charity Number: CHY 5507**

The information provided in this publication was correct and accurate at the time of publication to the best of the Irish Heart Foundation's knowledge.