

## **Privacy Impact Assessment for the Individual Health Identifier**

### ***A Submission by the Citizens Information Board (April 2016)***

The Citizens Information Board (CIB) welcomes the opportunity to comment on the Draft Privacy Impact Assessment for the Individual Health Identifier (IHI). The Board believes that overall the Privacy Impact Assessment Framework anticipates and makes provision for many of the potential privacy risks likely to arise. In particular, the Board welcomes the clear statement about the absolute distinction between the IHI and a person's electronic health record (EHR) – this distinction needs to be reiterated fully in any evolving or future usage of the IHI. Conducting a Privacy Impact Assessment (PIA) at the project planning stage of the introduction of the IHI is important. Provision for updating the PIA as the project progresses is also important.

#### ***People with Cognitive Impairment or Reduced Capacity***

Given our role in funding and supporting the National Advocacy Service for People with Disabilities (NAS), the CIB is particularly interested in the application of the IHI to people with an intellectual disability.<sup>1</sup>

There are particular difficulties associated with collecting data from or about people with cognitive impairment and/or reduced mental capacity and in ensuring their right to privacy. These difficulties have not been referenced in the Draft Privacy Impact Assessment framework and this is a matter of some concern. The particular difficulties related to ensuring that confidentiality is protected in respect of people with cognitive impairment in an electronic dataset (even the most minimum as envisaged in the IHI) need to be openly acknowledged and anticipated. This matter has become even more relevant since the passing of the Assisted Decision-making (Capacity) Act 2015 last December.

Since the PIA is based on an assessment process that facilitates the identification of potential privacy risks to a project prior to implementation, it is crucial that the potential risk related to people with cognitive impairment is included at the outset and that the appropriate safeguards are put in place.

The following relevant principles are identified by the CIB in respect of people with cognitive impairment.

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<sup>1</sup> In 2014, over 35% of people supported by NAS had an intellectual disability, 20% had a physical disability and nearly 20% had mental health issues. Issues addressed include moving out of institutional care, inappropriate accommodation, income support and access to personal finances, and quality of life issues.

- Any information recorded should be limited to that essential to the IHI and based on the principles of ‘need to know’ and ‘duty of care’;
- Information held on the IHI is confidential and should not be passed on to anyone (including relatives and health and social care personnel) without the individual’s knowledge and consent;
- Protocols need to be in place to deal with complex and specific situations where the principles of confidentiality and consent to the sharing of information have to be suspended;
- Where a person is deemed not to have capacity to give consent and to provide the information required for his/her IHI, there should be provision for another *bona fides* person to provide the information on his/her behalf (e.g., attorney with relevant authority under an Enduring Power of Attorney that has been registered, or a Decision-making Representative or Healthcare Representative appointed under the Assisted Decision-making (Capacity) Act 2015);
- Before providing information to a third party where a person cannot give consent or where it is unclear whether or not s/he is able to give consent, there is a need to ensure that as far as possible the divulgence of such information is required in order to ensure that s/he receives appropriate health or social care or to safeguard the person involved;

The implementation of the rules of data protection is likely to present significant challenges in respect of people with reduced capacity:

- Obtain and process information fairly
- Keep it only for one or more specified, explicit and lawful purposes
- Use and disclose it only in ways compatible with these purposes
- Keep it safe and secure
- Keep it accurate, complete and up to date

The principles relating to the sharing of information that apply before and during intervention in respect of people with reduced capacity as set out in Section 8 of the Assisted Decision-making (Capacity) Act 2015, in particular 8(10):

*The intervener, in making an intervention in respect of a relevant person—*

- (a) *Shall not attempt to obtain relevant information that is not reasonably required for making a relevant decision,*

*(b) Shall not use relevant information for a purpose other than in relation to a relevant decision, and*

*(c) Shall take reasonable steps to ensure that relevant information—*

*(i) is kept secure from unauthorised access, use or disclosure, and*

*(ii) is safely disposed of when he or she believes it is no longer required.*

The provisions for supported decision-making in the 2015 Act are also relevant to the way people are to be engaged in the IHI system. The legislation recognises different levels of decision-making capability and therefore provides for different categories of interveners to assist a person in maximising his or her capacity. The Act thus provides for three types of decision-making support options to respond to the range of support needs that people may have in relation to decision-making capacity.

- 1) *Assisted decision-making*: a person may appoint a decision-making assistant – typically a family member or carer – through a formal decision-making assistance agreement to support him/her to access information or to understand, make and express decisions;
- 2) *Co-decision-making*: a person can appoint a trusted family member or friend as a co-decision-maker to make decisions jointly with him or her under a co-decision-making agreement;
- 3) *Decision-making representative*: for the small minority of people who are not able to make decisions even with help, the Act provides for the Circuit Court to appoint a decision-making representative.<sup>2</sup>

### **Other Points**

- There is a need for greater clarity about access by private health and social care providers, e.g., private nursing homes to IHI information and how this should be used;
- It is essential that processes are in place for the safe and secure electronic transfer of data – the protocols for transferring data from the Public Service Identity Register will be particularly important in this regard;

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<sup>2</sup> A decision-making representative will make decisions on behalf of the person but must abide by the guiding principles and must reflect the person's will and preferences where possible. The functions of decision-making representatives will be as limited in scope and duration as is reasonably practicable.

- Any statistical data or case evidence about people being put into the public domain for research, policy development or monitoring and evaluation purposes should at all times be presented anonymously and not traceable to any individual or group;
- The ongoing review of processes and procedures in respect of protecting privacy is crucial, particularly if any changes are introduced to the usage of the IHI register.