HPO Data Protection Statement

1. The Healthcare Pricing Office (HPO)

The Healthcare Pricing Office (HPO) is the section within the HSE that is responsible for the implementation of the Activity Based Funding (ABF) model in Irish acute hospitals. The office was established in 2014 to implement the Government's commitment to introducing an ABF model in Ireland. The Government committed to the introduction of ABF in its "Programme for Government" and in "Future Health: A Strategic Framework for Reform of the Health Service" (2012) and published details on how the model would operate in the "Policy Paper on Hospital Financing" (2013).

As well as being responsible for the implementation of ABF, the HPO is also responsible for the management of a number of national data collections including the training, coding and audit functions associated with those collections. These data collections are used for the management and planning of the Irish healthcare system as well as being used for ABF purposes.

2. Data protection at the HPO

As the office responsible for the management of a number of national data collections, we at the HPO take our data protection responsibilities very seriously. We recognize that holding the information contained in these data collections requires that all appropriate measures are taken to ensure that this data is collected, stored and utilized in line with regulations and best practice guidelines in a secure and transparent manner.

In particular, we adhere to <u>The Data Protection Acts 1998 to 2018</u> and Regulation (EU) 2016/679 of the European Parliament and the council of 27 of 27 April 2016 also known as the <u>General Data Protection Regulation</u> or GDPR. These acts and regulations set out what the rights of individuals' are in relation to their personal data and what the responsibilities are for organisations that collect, store and process this data.

In addition to adhering to national and international law, the HSE has also developed national IT and data protection policies which apply to the HPO. These policies cover areas such as information security, access control, data encryption, password standards, data sharing, information classification and handling and data protection breach management. These policies have been put in place to help ensure that data is collected, stored and processed according to the appropriate legislation and best practice guidance.

3. Information collected by the HPO

In general, the HPO collects and processes the minimum amount of information required to fulfill its functions. In particular, the national data collections managed by the HPO do not contain patient names, addresses or contact details.

Hospital In-Patient Enquiry System

The Hospital In-Patient Enquiry (HIPE) system collects information on inpatient and daycase patients discharged from Irish acute public hospitals. The information collected includes clinical, administrative and demographic data. Clinical information includes details of diagnoses and procedures carried out on each patient. Administrative information includes items such as dates and times of admission and discharge, type of admission, source of admission and discharge location. Demographic information collected includes gender, month and year of birth, county of residence and the first three characters of the Eircode.

The national HIPE database, held within the HPO, does not collect patient names, patient addresses, telephone numbers, medical card numbers or full date of birth. It does collect each patient Medical Record Number (MRN) which is a number assigned to each patient by the hospital that they attend. However, the HPO does not hold information which could be used in conjunction with the MRN to identify an individual patient by name.

For full details on data collected please refer to the <u>HIPE Data Dictionary</u> and the <u>HIPE Instruction</u> <u>Manual</u>.

National Perinatal Reporting System

The National Perinatal Reporting System (NPRS) collects information on perinatal events nationally. Information on every birth in the Republic of Ireland is submitted to the NPRS. All births are notified and registered on a standard four part birth notification form (BNF01) which is completed where the birth takes place. Part 3 of this form is sent to the HPO for data entry and validation. The information collected includes clinical, administrative and demographic data.

Clinical information includes details of infant's birth weight, period of gestation, mother and infant diseases/conditions, mother's obstetric history, perinatal death information and method of delivery. Administrative information includes items such as type of birth indicator (live birth or stillbirth), place of birth (hospital, domiciliary or born before arrival), type of antenatal care received including dates of first visit to doctor or hospital during pregnancy, type of feeding, booking information including dates of admission and discharge. Demographic information collected includes gender, dates of birth (infant, mother and father), father and mother county of residence, nationality and occupation.

The NPRS does not collect patient names, patient addresses, PPSN or GP details. The time frame to which the information relates is from pregnancy until 7 days after the delivery.

For full details on data collected on NRPS go to http://www.hpo.ie/nprs/nprs documentation/NPRS Data Dictionary 2015 V1.2.pdf

Patient Level Costing Programme

The Patient Level Costing (PLC) programme, which is run by the HPO in conjunction with participating hospitals, uses HIPE data, hospitals' financial data and information from clinical and administrative systems within the hospital to derive the estimated cost of treating individual cases.

The PLC programme does not collect patient names, patient addresses, telephone numbers, medical card numbers or full date of birth. In instances where such information is contained in the files

submitted by hospitals, the information is deleted. The information derived from clinical systems relates to service usage only i.e. which patient received which services.

Information Request Contact Details

The HPO maintains a database of information relating to requests for information which have been received by the office. These requests can come in the form of parliamentary questions (PQs), requests under the Freedom of Information Act (FOI), press queries, requests from academic researchers or from the general public. On receipt of such a request, the requestors contact details including name, address, phone number & email address as added to the database along with details of the request and how it was answered. This information is only used to deal with information requests as initiated by the requestor and the HPO will only contact individuals in relation to the requests they have submitted. Personal information on requestors is held for a period of 3 years after the request has been received.

Work Related Records

In addition to the data collections mentioned above, which can be generally considered relate though not exclusively, to members of the public, the HPO also maintains a number of databases which relate to persons who work within the healthcare system. The data contained in these systems relates only to the person in their capacity as an employee of the healthcare system and the HPO only collects this information in order to fulfill its functions. Such collections include:

Contact details and training records of HIPE coders

HIPE training records are held by the HPO indefinitely for the purposes of planning and management of the HIPE function at national and to support local HIPE management and HIPE clinical coders.

Consultant names and medical council numbers

The national HIPE database contains encrypted consultant identifiers which record which consultants had particular input in a case. In order to facilitate this, the HPO maintain a list of consultant names and medical council numbers. These are used to allocate a unique HIPE number to each consultant. Although the HPO assigns the HIPE consultant numbers, we only receive an encrypted version of it on the HIPE data returned from each hospital. This ensures that consultants can only be identified on the local HIPE system from within the hospitals in which theywork.

4. How your data is collected

Hospital In-Patient Enquiry System

Each acute hospital in Ireland has a local installation of the HIPE system. Patients' demographic and administrative data are transferred from the hospital Patient Administration System (PAS) into the local HIPE installation. The clinical information is then entered onto the local HIPE system by teams of clinical coders using the patient charts. Once a month, each hospital securely uploads their local HIPE data to the HPO for inclusion in the national HIPE file. It is during this uploading process that individual patient identifiers such as name, medical card number, and day of birth are removed to ensure patient confidentiality is maintained. www.hpo.ie

National Perinatal Reporting System

All births in Ireland are notified and registered on a standard four part birth notification form (BNF01) which is completed where the birth takes place. Part 3 of this form is sent to the HPO for entry on to the NPRS national file.

Patient Level Costing Programme

In addition to the data collected from the HIPE system, the PLC programme utilizes financial data from the General Ledger of each hospital and information from the various clinical systems in those hospitals to derive costs at the individual case level. The processing of PLC data is facilitated through specialized patient level costing software. The HIPE data for the PLC programme is taken directly from the national HIPE database and the financial data from the hospitals' financial systems. The collection and linking of data from clinical information systems is carried out by the hospitals' costing staff. Once the PLC costing has been carried out, a summary of the data is then transferred to a central database held by the HPO for use in ABF. This PLC exercise is carried once a year by each of the participating hospitals. www.hpo.ie

Information Request Contact Details

Contact details relating to requestors of information are taken from the requesting email and added to our database for use in dealing with the current and any future requests from that individual. If consent is granted by the requestor then this information is stored on our database for a period of 3 years after the request has been received. If consent is not granted then the requestor's contact details are deleted from the database once the request has been answered.

Work Related Records

Contact details and training records of HIPE coders

On registering for HIPE coder training, each coder's details are added to the coder training database. As additional training is undertaken the training records are updated to reflect this. In addition, contact details are updated when necessary to reflect changes in location, title etc.

Consultant names and medical council numbers

When consultants begin working in a hospital, the local HIPE coding team send no their details to the HPO and request a HIPE consultant number. On receipt of the information, the HPO team checks the current database to see whether the consultant is already listed. If they are, then the hospital is issued with the existing HIPE number. If not then their details are added to the database and a new HIPE consultant number is issued.

5. How your data is used

The principal use of the data collected by the HPO is the planning, monitoring and management of the healthcare system in Ireland. The HIPE and NPRS systems each contain a rich source of information which the HSE utilises to make evidence informed decisions and further develop the healthcare system. This use of your data helps the HSE to continually improve the services available to patients in Ireland. For instance this data can be used to help explore questions such as:

- How are services currently configured and how should they be configured to best serve the Irish population?
- How is the aging population likely to change the demand for healthcare in the coming years?

• What funding should be allocated to each hospital based on the mix of patients that they treat? This is the basis of the ABF funding model. www.hpo.ie

In addition to its use in healthcare service planning and management, the data collected by the HPO, is used to answer information requests from a variety of sources including parliamentary questions, requests under the Freedom of Information Act, requests from academic researchers, requests from students, requests from companies and from members of the public. In relation to these requests for information the HPO -

- Does follow data protection guidelines in relation to the use and processing of the data that it collects
- **Does** require requestors to sign terms and conditions prior to the release of information.
- **Does** provide aggregate level summary data with the condition that any cells with a count between 1 and 5 are suppressed.
- **Does** provide guidance on the correct usage of the information provided including restrictions on publication of the information.
- Does provide fully anonymised record level data to academic researchers where the
 requirement for record level data has been sufficiently justified. Fully anonymised means that
 the MRN has either been encrypted or removed and any other identifying fields have been
 ether removed or reduced to an aggregated form (e.g. province of residence rather than
 county of residence) before providing the data. In such cases only the minimum number of
 data fields required for the analysis is released.
- **Does** stipulate in user agreements relating to datasets the security measures to be put in place by the recipient the and duration of time that the information can be held for.
- Does provide aggregate level summary data to companies for the purposes of carrying out cost benefit analyses and making new product submissions to the HSE
- **Does** allow third parties who are contracted to carry out work on behalf of the HPO to the HSE to process data for a specific purpose and duration of time under strict security arrangements and in adherence with GDPR.
- **Does not** carry out any processing or analytics on data for the purposes of individual patient profiling.
- **Does not** release or publish any summary data where the counts are less than 5.
- **Does not** in any way attempt to use data in our possession in conjunction with other data sources to identify individual patients.
- **Does not** allow identifiable personal data to be held for any purpose or under any security arrangements outside of the jurisdiction of the Republic of Ireland.
- **Does not** sell data to third parties
- **Does not** contact individuals from our information request database for any reason other than dealing with their request.

5. The legal basis for collecting your data

The legal basis for the collection of HIPE, NPRS and PLC data by the HPO is given in the <u>Health Act</u> 2004 which established the HSE on a legal basis and Article 2B of <u>the Data Protection Acts 1988 and 2003</u> which deals with the processing of personal sensitive data. Section (1) of article 2B states that

[&]quot;Sensitive personal data shall not be processed by a data controller unless.......

(viii) the processing is necessary for medical purposes and is undertaken by -

(I) a health professional, or

(II) a person who in the circumstances owes a duty of confidentiality to the data subject that is equivalent to that which would exist if that person were a health professional, "

Article 2B further clarifies that

"health professional' includes a registered medical practitioner, within the meaning of the Medical Practitioners Act, 1978, a registered dentist, within the meaning of the Dentists Act, 1985, or a member of any other class of health worker or social worker standing specified by regulations made by the Minister after consultation with the Minister for Health and Children and any other Minister of the Government who, having regard to his or her functions, ought, in the opinion of the Minister, to be consulted;"

And that

"medical purposes' includes the purpose of preventive medicine, medical diagnosis, medical research, the provision of care and treatment and the management of healthcare services."

In addition, the basis for the collection of NPRS data is given in the Notification of Births Act, 1907 and Notification of Births (Extension) Act, 1915. These Acts form the basis for the requirement of those in attendance of each birth to notify the event of a birth. Notification of a birth is required to proceed to registration of a birth, which is a legal requirement in the state of Ireland.

7. How long we hold your data

Due to the importance of the data collected by the HPO in the planning and management of health services, the data that is collected is held in perpetuity. Retention of this data over long periods of time allows for the identification and examination of trends which can ultimately be used to improve the healthcare system.

8. Your rights in relation to your data

Under the General Data Protection Regulation (GDPR) you have rights in relation to how your personal data is collected and processed. In general, under GDPR you have the right to:

- know if your data is being used
- know how your data is being used
- receive a copy of your data
- have inaccuracies corrected
- restrict the use of your data
- have your data deleted
- withdraw consent where collection and processing is based on consent

Due to the secure manner in which data is collected for the HIPE and NPRS databases, it is not possible for us to identify data relating to particular individuals and this restricts our ability to take direct action in relation to some of these rights. For instance it is not possible for us to amend or delete records relating to particular individuals, restrict the processing of data relating to articular individuals or to provide a record of the data that is held relating to particular individuals.

However, given that the national data collections are a reflection of the records held in Irish hospitals it is possible for you to exercise your right to receive a copy of your data and have

inaccuracies corrected by contacting the hospital directly. Any amendments made to your medical records while the national data collection is still open will be reflected in that national data collection. However, once the database is considered to be closed then changes will be made only if there is a major problem identified.

Where data is held on requestors of information, all of the above rights can be exercised by contacting the HPO.

9. Who to contact in relation to data protection

Queries, complaints or requests relating to data protection at the HPO should, in the first instance, be addressed to:

Dr Steeven's Hospital, Steeven's Lane, Dublin 8

Telephone: +353 (01)-6352726

Email: dpo@hse.ie

WWW: https://www.hse.ie/eng/gdpr/

Queries or complaints in relation to data protection can also be addressed to

The Office of the Data Protection Commissioner at:

Data Protection Commission, Canal House, Station Road, Portarlington, R32 AP23, Co. Laois.

Telephone: +353 (0)761 104 800 or Lo Call Number 1890 252 231

Fax: +353 57 868 4757

E-mail: <u>info@dataprotection.ie</u> WWW: <u>www.dataprotection.ie</u>

10. Updates to our data protection statement

This data protection statement may be updated from to time to reflect changes in legislation and/or guidelines or changes in the data that are collected by the HPO. Any such changes will be posted on our website including the date that it was last updated.

Data Protection Statement last updated: November 2019