Príomhoifigeach Cliniciúil Oifig an Phríomhoifigigh Cliniciúil

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HSE PRIVACY NOTICE -

Patients, Service Users and Staff of Childrens Health Ireland ("CHI") and the National Orthapaedic Hospital Cappagh ("Cappagh")

Independent External Review (the "Review") commissioned by Dr. Colm Henry, Chief Clinical Officer, HSE to be conducted by Mr. Selvadurai Nayagam BSc, MCh(Orth), FRCS Ed (Trauma and Orth), Consultant in Orthopaedics and Trauma and Head of the Limb Reconstruction (the "Independent Reviewer").

1. Purpose

The Health Service Executive (HSE) must comply with the Data Protection Acts 1988-2018 and the General Data Protection Regulations (GDPR). The purpose of this privacy notice is to explain how HSE will collect and use personal information for the purpose of the Review commissioned by HSE as referred to above.

The persons whose personal data may be processed for the purpose of this Review include patients of CHI and Cappagh whose treatment/care may be reviewed under the Terms of Reference for the Review, and staff of CHI and Cappagh who may have been involved in the care/treatment of patients whose treatment/care is being reviewed by the Independent Reviewer for the purpose of this Review.

2. Background

The Health Service Executive is tasked with improving, promoting and protecting the health and welfare of the public, pursuant to Section 7 of the Health Act 2004 and is the State's public health service provider.

Under Section 38 of the Health Act 2004, HSE may enter into an arrangement with another party for the provision of a health or personal social service by that party on behalf of HSF.

HSE has entered into a Service Arrangement under Section 38 with Childrens Health Ireland ("CHI") and (separately) with the National Orthapaedic Hospital Cappagh ("Cappagh").

CHI and Cappagh are (separately) funded by HSE pursuant to Section 38 of the Health Act 2004.

Further to certain patient safety concerns in relation to spinal surgery for patients with Spina Bifida at CHI at Temple Street identified in 2022, a number of reviews/reports were commissioned by CHI.



In or about September 2023, HSE (and in particular Dr. Colm Henry, Chief Clinical Officer, HSE) commissioned an External Expert, Mr. Selvadurai Nayagam, (the Independent Reviewer) to conduct an independent review of elements of the Paediatric Orthopaedic Surgery Service at Childrens Health Ireland ("CHI") and the National Orthapaedic Hospital Cappagh ("Cappagh") to provide independent assurance in regard to the current and future provision of the service. The Terms of Reference for the Review are **attached**.

3. Who is the data controller?

HSE and the Independent Reviewer are Joint Data Controllers in relation to the personal information (personal data of service users/patients and staff) collected and used for the purpose of this Review.

This Privacy Notice is issued by the HSE as one of the Joint Data Controllers. A separate privacy notice has been issued by the other Joint Data Controller, the Independent Reviewer.

Notwithstanding that HSE and the Independent Reviewer are Joint Data Controllers for data protection purposes in relation to the Review, the Independent Reviewer retains full clinical independence in the conduct of the Review and is fully independent of the HSE in conducting the Review.

As the HSE and the Independent Reviewer are Joint Data Controllers of personal data processed for the purpose of the Review, the HSE and the Independent Reviewer have entered into an agreement setting out how we will carry out our respective responsibilities to comply with GDPR and the Data Protection Acts 1988 – 2018.

The Independent Reviewer will be responsible for managing data subject rights requests while the Review is ongoing, and HSE will be responsible for dealing with data subject rights requests once the Review is completed. Please see sections 11 and 17 below for contact details.

4. How we obtain your information

For the purpose of conducting this Review, CHI and Cappagh will be providing your information to the Independent Reviewer (as authorised by HSE) pursuant to a legal obligation on those third parties to provide your information to HSE. The legal obligation in question is set out in Section 38 of the Health Act 2004 and this statutory obligation is reflected in a contractual obligation in the Service Arrangement between HSE and CHI or Cappagh to provide information on services provided if and when requested by HSE.

The HSE have directed that all information necessary for the conduct of the Review by the Independent Reviewer should be provided by CHI and Cappagh directly to the Independent Reviewer, as opposed to being provided to HSE and then in turn furnished to the Independent Reviewer.



From a practical perspective, the HSE will not be provided with access to your personal data by the Independent Reviewer during the Review. The HSE may be in receipt of some personal data of patients/employees directly from CHI or from Cappagh in certain circumstances during the Review e.g. pursuant to queries raised by patients/employees concerning the Review which require a response from the HSE.

Alternatively, or in addition, HSE may be in receipt of your personal data if you provide information to us during or after the Review.

The HSE will take possession and control of the personal data processed by the Independent Reviewer for the purposes of the Review after the Review has been completed, and will securely retain the personal data for safekeeping in line with the relevant Retention Period.

HSE have facilitated the Independent Reviewer with a confidential secure shared drive and secure email accounts on which electronic records for the Review may be held/stored during the period whilst the Review is ongoing. Access to these facilities is restricted to and under the control of the Reviewer and his administrative team. In addition, the Reviewer may use certain facilities for secure communication and storage of records through Grant Thornton (which is providing administrative support to the Review). Grant Thornton is an authorised service provider and data processor of the HSE.

Where the Independent Reviewer engages specialist expert advisors pursuant to the Terms of Reference for the Review, the Independent Reviewer may grant access, as appropriate and necessary, to certain records or personal information relevant to their role in assisting the Independent Reviewer.

The Independent Reviewer has put in place certain secure measures to ensure the security of any communications undertaken for the purpose of the Review and these are set out in the Privacy Notice of the Independent Reviewer.

5. The information we process about you

For the purpose of conducting the Review, various categories of your personal information will be processed/collected:

In relation to patients/service users, the information collected and processed about you may include:

- Personal details, such as name, date of birth, address, next of kin, contact details (mobile phone number) etc.
- Names and contact details of parents/guardians where patient is a minor
- Information relating to medical treatment and care; notes and reports about your health and your treatment; results of investigations, relevant imaging such as x-rays/scans, blood tests, correspondence relating to your care/treatment
- Relevant information from other health and social care professionals, other healthcare agencies and your carers and relatives



In relation to staff of CHI or Cappagh, the information collected and processed about you may include:

- Personal details such as name, contact details
- Details of role/position, qualifications and experience, registration number with professional regulatory body
- Any other personal data of staff which may be included in documentation furnished to the HSE or the Independent Reviewer for the purpose of the Review

As above, HSE have directed that all information necessary for the conduct of the Review by the Independent Reviewer should be provided by CHI and Cappagh directly to the Independent Reviewer, as opposed to being provided to HSE which means that from a practical perspective, the HSE will not be provided with access to your personal data by the Independent Reviewer during the Review. The HSE may be in receipt of some personal data of patients/employees directly from CHI or from Cappagh in certain circumstances during the Review e.g. pursuant to queries raised by patients/employees concerning the Review which require a response from the HSE.

Alternatively, the HSE may be in receipt of your personal data if you provide information to us during or after the Review.

6. How do we use your information?

Your information will be used in the following manner:

For the purpose of initiating and conducting the Review in accordance with the Terms of Reference of the Review including to identify any risks or concerns around the care provided by the Service Provider (CHI and Cappagh) and to assess, monitor and review the care and treatment provided to ensure it is of the highest standard possible, to evaluate and improve the safety of our services as provided by the Service Provider.

As above, HSE have directed that all information necessary for the conduct of the Review by the Independent Reviewer should be provided by CHI and Cappagh directly to the Independent Reviewer, as opposed to being provided to HSE and then in turn furnished to the Independent Reviewer which means that from a practical perspective, the HSE will not be provided with access to your personal data by the Independent Reviewer during the Review. The HSE may be in receipt of some personal data of patients/employees directly from CHI or from Cappagh in certain circumstances during the Review e.g. pursuant to queries raised by patients/employees concerning the Review which require a response from the HSE.

Alternatively, the HSE may be in receipt of your personal data if you provide information to us during or after the Review.

The HSE will take possession and control of the personal data processed by the Independent Reviewer for the purposes of the Review after the Review has been



completed, and will securely retain the personal data for safekeeping in line with the relevant Retention Period.

7. Legal basis for processing your personal data

The HSE's lawful basis for processing your personal data in relation to the Review is as follows:

The processing is necessary for a task carried out in the public interest or in the exercise of official authority vested in the controller, as set out in Article 6.1.(e) of GDPR

Official authority is vested in HSE under the Health Act 2004 (as amended) including Section 7 and Section 38 thereof.

Special categories of data are defined by the GDPR and include things like racial or ethnic origin, religious or philosophical beliefs, genetic data, biometric data, health data, sex life details and sexual orientation.

The processing of your special category data is necessary for the purpose of the Review for reasons of substantial public interest, as set out in Article 9.2. (g) of GDPR, and for reasons of public interest in the area of public health and ensuring high standards of safety of health care and medical devices, as set out in Article 9.2. (i) of GDPR.

The Review is being conducted to monitor/review the standard of certain public health services provided by CHI and Cappagh on behalf of HSE. HSE has an entitlement to monitor the provision of such services pursuant to Section 38 of the Health Act 2004 and pursuant to the contractual Service Arrangements in place with those Service Providers (CHI and Cappagh).

8. Specific measures to safeguard the rights and freedoms of the data subject

Where reliance is placed on the legal bases under Article 9(2)(g) and Article 9(2)(i) GDPR HSE and the Independent Reviewer are obliged to provide for and/or put in place what are called "suitable and specific measures" to safeguard the rights of persons whose personal data is processed as part of the Review.

From HSE's perspective, the following safeguards are in place to safeguard the rights and freedoms of persons whose personal data is processed as part of the Review:

- A professional duty of confidentiality is a requirement so that the personal data of data subjects is protected. The Reviewer appointed to conduct the Review is a medical professional who has a professional duty of confidentiality in relation to any personal data and special category data he processes whilst conducting the Review.
- In general, access to special category data e.g. patient medical information, for the purposes of the Review is limited to the Independent Reviewer, specialist



expert advisors whom he may engage for the purpose of assisting him in the Review and the Independent Reviewer's administrative support person. The specific access restrictions are within the control of the Independent Reviewer. In addition password protection will be in use for the purpose of personal data transmitted electronically.

- A documentation request protocol has been developed and put in place between CHI and the Independent Reviewer, and a separate documentation request protocol has been developed and put in place between Cappagh and the Independent Reviewer, which records and ensures clear parameters around the precise records/documentation which the Independent Reviewer will access.
- The Independent Reviewer will ensure that special category data will be anonymised or pseudonymised where appropriate during the course of the Review
- The Independent Reviewer will be required, in completing the Review Report, to ensure that individual data subjects are not identified or identifiable in so far as possible. It may be possible for data subjects to identify themselves from the Report or it may be possible where publicly accessible information is available for readers of the Report to identify persons referred to within the Report.
- In terms of retention of personal information including special category data, time limits will be applied for erasure of the data in line with the HSE Incident Management Framework 2020 (7 years or for children where the statute of limitation for personal injury claims is two years less a day from the date of their 18th birthday).

9. What other use is made of your Information

HSE may use information set out in the Review Report to consider and pursue follow up actions, implement recommendations of the Report, for service planning purposes or for audit or learning purposes.

HSE provides aggregated or statistical information to other organisations such as the Department of Health, universities and other research institutions. The HSE will make sure that individuals cannot be identified by anonymising the information. If it is not possible to anonymise the information, you will be contacted for your consent.

10. Your rights

You have certain legal rights concerning your information and the manner in which we process it. This includes:

- A right to know whether the data controller is processing your personal information. This is one of the purposes of this Privacy Notice.
- A right to get access to your personal information;
- A right to request us to correct inaccurate information, or update incomplete information;
- A right to request that we restrict the processing of your information in certain circumstances;



- A right to request the deletion of personal information in certain circumstances, excluding medical records;
- A right to receive the personal information you provided to us in a portable format;
- A right to object to us processing your personal information in certain circumstances, including for the purpose of automated decision making (computer-made) or for the purpose of profiling - HSE do not intend to use any personal information for the purposes of automated decision-making or profiling.
- Where the processing of personal data is based on point (e) or (f) of Article 6(1), (as it is for the purpose of the Review), a data subject has an entitlement to object to processing of their data at any time, under Article 21 of GDPR, on grounds relating to his or her particular situation. If you exercise your right to object to processing of your information by HSE or the Independent Reviewer under Article 21 GDPR, in order for the HSE or the Independent Reviewer to continue processing your information they must demonstrate "compelling legitimate grounds" to do so, being grounds which override your interests, rights and freedoms.
- A right to lodge a complaint with the Data Protection Commission (DPC).
 Contact details for the DPC are available at www.DataProtection.ie

Some of these rights only apply in certain circumstances and so are not guaranteed or absolute rights.

Please contact the HSE Data Protection Officer if you have any queries or concerns about your rights or about this Privacy Notice.

11. Invoking your rights and access to your personal information

As HSE and the Independent Reviewer are Joint Data Controllers, we have entered into an agreement setting out how we will carry out our respective responsibilities to comply with GDPR and the Data Protection Acts 1988 – 2018.

We have agreed that, while the Review is ongoing, for the purpose of invoking your rights and/or accessing your personal information, you may do so by contacting the Independent Reviewer using the following contact details:

The nominated contact person for the Review is as follows:

• Ms Lauren Byrne Email: lauren.byrne5@hse.ie

Contact details for the Independent Reviewer are as follows:

• Mr Selvadurai Nayagam Email: selvadurai.nayagam1@hse.ie

If seeking to access your personal information, it is important that you provide satisfactory evidence of identification and a sufficient description of the information that you are looking for when seeking access to your information.



Once the Review has been completed, you may invoke your rights and/or access your personal information by contacting the HSE Data Protection Officer using the contact details below:

Email: dpo@hse.ie

12. Categories of recipients of your personal data

Within the HSE, the personal data collected about you will only be accessed as considered absolutely necessary for the reasons set out above (where possible, personal information is anonymised or pseudonymised).

The personal data may, only where necessary, be given to third parties who we engage to provide services to us such as outsourced service providers, IT services providers, professional advisers, auditors.

In certain situations, we may have to disclose your personal information to other agencies, in accordance with legal requirements, i.e. Department of Health, the Courts etc., or where necessary we may disclose your personal information in order to make a referral to any appropriate third party in the event a significant concern arises e.g. HIQA, HPRA, Tusla, An Garda Siochana etc.

HSE will share your information with the Independent Reviewer and his administrative team where such information is relevant for the purposes of the Review.

13. Transferring information abroad

We may transfer your information to third parties in other countries where necessary for the purposes of processing set out above, on the basis that anyone to whom we pass it protects it in the same way we would and in accordance with applicable laws. In particular, as the Independent Reviewer is primarily UK based, as are some of the specialist expert advisors whom the Independent Reviewer may engage for the purpose of the Review, you should be aware that access to your personal data may be gained by those parties from the UK. The European Commission has made decisions on the UK's adequacy under GDPR which means that it recognises that UK provides adequate and equivalent protection for personal data transferred from the EU to the UK.

14. How do we keep your records secure and confidential?

We are committed to ensuring that your information is secure with us and with the third parties who act on our behalf. We have a number of security precautions in place to prevent the loss, misuse or alteration of your information. All staff working for the HSE have a duty to keep information about you confidential. The HSE has strict information security policies and procedures in place to ensure that information about you is safe, whether it is held in paper or electronic format.

During the course of the Review, the Independent Reviewer is responsible for securely storing and processing the personal data processed by the Independent Reviewer for the purposes of the Review.



Once the Review Report has been completed, the HSE will take possession and control of the personal data processed by the Independent Reviewer for the purposes of the Review, and will securely retain the personal data for safekeeping in line with the relevant Retention Period.

15. Retention period

We will not hold your Personal Data for longer than is necessary. We will retain your personal data for:

- (a) as long as we need it for the purposes described in this Notice; or
- (b) to comply with any legal or regulatory obligations; or
- (c) if relevant, to deal with any claim or dispute that might arise between you and us.

In terms of retention of personal information including special category data, time limits will be applied for erasure of the data in line with the HSE Incident Management Framework 2020 (7 years or for children where the statute of limitation for personal injury claims is two years less a day from the date of their 18th birthday).

16. Updates/Changes to this Privacy Notice

HSE may amend or update this Notice at any time. You are encouraged to periodically review this notice or you may request an up to date copy of this Notice at any time, using the contact details set out above.

17. Contact details

Please contact our Data Protection Office:

- If you have any queries in relation to Data Protection or other issues around the security of your personal information
- For more information about the steps we are taking to protect your information
- For more information about your rights, including the circumstances in which you can exercise them and how to exercise them
- If you wish to raise a complaint on how we have handled your personal information, you can contact our Data Protection Officer who will investigate the matter. We hope that we can address any concerns you may have.

National Data Protection Officer Email: dpo@hse.ie

16 January 2024