



**HEALTH RESEARCH IN THE HSE
PRIVACY STATEMENT ON PRE-SCREENING ACTIVITIES AND THE APPOINTMENT OF
AN AUTHORISED PERSON**

Document Information

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The HSE supports and carry out health research to high ethical standards to benefit patients, improve patient care and the health system.

Your participation in health research is voluntary and will not affect the care and treatment you receive from the HSE.

1. Patients Personal Data

The HSE holds the personal data of patients who have received healthcare services in the HSE.

The management of your personal data is the responsibility of the HSE as a Data Controller. The HSE has appointed a Data Protection Officer (Head DPO) and Data Protection Officers to make sure your personal data are accessed and processed in the right manner.

If you have any questions regarding the usage of your personal data, please contact dpo@hse.ie

For more information on how your personal data are processed in the HSE: www.hse.ie/eng/gdpr

For more information on health research and data protection: <https://hseresearch.ie/data-protection-and-research/>

2. Pre-Screening Of Patients Personal Data and the Law

The law permits in certain circumstances to use your personal data without your consent to establish if you might be a suitable candidate for inclusion in a particular health research study. This is called pre-screening.



- **Legal basis for processing personal data for Pre-Screening without Explicit Consent: GDPR 9(2)(i) & Regulation 4 (c) of the Data Protection Act 2018 (Section 36(2)) (Health Research) (Amendment) Regulations 2021 (S.I. No. 18 of 2021)**

7. What is Pre-Screening

Pre-Screening are activities used by a research active person (e.g. a research nurse) to establish if you might be a suitable candidate for inclusion in a particular health research study.

It involves reviewing medical records of patients who have received health services in the HSE. Only personal data necessary to establish if you are a suitable candidate will be accessed.

It does not mean that you will be recruited into the health research study, but simply that you may be eligible.

Suitable candidates may subsequently be contacted by the HSE or an Authorised Person who is a health professional to establish:

- their interest in taking part in the health research study,
- if they want and consent to be contacted by the research team.

8. Who Can Conduct Pre-Screening

Your personal data can only be accessed by:

- a **health practitioner employed by the HSE** (e.g. a registered doctor or a registered nurse)
- a **health student supervised by a health practitioners employed by the HSE**
- a **HSE employee who ordinarily access your data** (e.g. medical records clerk)
- a limited number of research active persons called '**Authorised Person**' who are appointed by the HSE' (e.g. a research nurse)

9. The Authorised Person

Sometimes the HSE may appoint a research active person (e.g. a research nurse) who is not an employee of the HSE to conduct pre-screening activities. This person is called an Authorised Person.

A limited number of research active persons may be appointed as an Authorised Person.
An Authorised Person must be an employee of:

- a Higher Education Institution (a University)
- a registered charity which supports research and education (e.g. Irish Heart Foundation)
- a practice which provides, manages or develop healthcare practitioners (e.g. ICGP)

10. The Appointment of an Authorised Person

A legal Agreement between the HSE and the employer of the Authorised Person regulates the appointment and pre-screening activities of an Authorised Person.

Under this Agreement an Authorised Person must:

- be appropriately Garda vetted before they can be appointed
- only access, process and use your records to establish if you are a suitable candidate for inclusion in a specific research study (the pre-screening activities)
- be under the control and direction (supervised) of a health practitioner employed by the HSE when they conduct the pre-screening activities
- be granted permission for each specific health research study, rather than a blanket permission (i.e. which would not involve any restriction).

Any access or use of your personal data outside the purpose of establishing your suitability or eligibility for inclusion of a health research study will be a breach to this Agreement and result in sanctions.

11. How long do you hold onto my personal data?

Provision of healthcare services by the HSE:

The HSE will retain your information for as long as necessary to provide you with services, and to comply with our legal and regulatory obligations. We are committed to protecting your personal data to the very best of our ability and take the appropriate steps to do in collecting, storing and destroying your data.

Pre-Screening activities:

Records from Pre-Screening activities will never be kept for longer than required for the purpose of conducting the pre-screening activities

12. What are my rights relating to personal data?

Provision of healthcare services by the HSE:

You have the following rights under the GDPR in relation to your personal data.

- **Right to access the data** – you have the right to request a copy of the personal data that we hold about you, together with other information about our processing of that personal data.
- **Right to rectification**- you have the right to request that any inaccurate data that is held about you is corrected, or if we have incomplete information you may request that we update the information such that it is complete.
- **Right to erasure** – you have the right to request us to delete personal data that we hold about you. This is sometimes referred to as the right to be forgotten.

- **Right to restriction of processing or to object to processing** – you have the right to request that we no longer process your personal data for particular purposes, or to object to our processing of your personal data for particular purposes.
- **Right to data portability** – you have the right to request us to provide you, or a third party, with a copy of your personal data in a structured, commonly used machine readable format

Some of these rights only apply in certain circumstances; they are not guaranteed or an absolute right. Please contact our Data Protection Officer if you have any questions or concerns about your rights. If you make a request, we have one month to respond to you.

Pre-Screening activities applicable rights:

Right to access the data: you have the right to request a copy of your personal data that were accessed for pre-screening activities.

Right to restriction of processing or to object to processing – you have the right to request that we no longer process your personal data for pre-screening activities, or to object to our processing of your personal data for that particular purpose.

13. How to make a complaint?



You have the right to make a complaint if you feel unhappy about how we hold, use or share your information.

To make a complaint directly to the hospital see the contact information for the Data Protection Officer below.

Data Protection Officer HSE	Email: dpo@hse.ie Phone: 087-9082160
Deputy Data Protection Officer West, (excluding voluntary agencies) Consumer Affairs, Merlin Park University Hospital, Galway. <ul style="list-style-type: none"> • CHO 1 – Cavan, Donegal, Leitrim, Monaghan, Sligo • Community Healthcare West – Galway, Mayo, Roscommon • Mid-West Community Healthcare – Clare, Limerick, North Tipperary. • Saolta Hospital Group 	Email: ddpo.west@hse.ie Phone: 091-775 373
Deputy Data Protection Officer Dublin North-East (excluding voluntary hospitals and agencies) Consumer Affairs, HSE Dublin North East, Bective St., Kells, Co Meath. <ul style="list-style-type: none"> • Midlands, Louth, Meath Community Health Organisation • Community Health Organisation Dublin North City & County • CHO 6 – Dublin South East, Dublin South & Wicklow • RCSI Hospital Group • National Children’s Hospital 	Email: ddpo.dne@hse.ie Phone: Kells Office: 046-9251265 Cavan Office: 049-4377343
Deputy Data Protection Officer Dublin mid-Leinster (excluding voluntary hospitals and agencies) Consumer Affairs, HSE, Third Floor Scott Building, Midland Regional Hospital Campus, Arden Road, Tullamore, Co. Offaly. <ul style="list-style-type: none"> • Dublin Midlands Hospital Group 	Email: ddpo.dml@hse.ie Phone: Tullamore Office: 057-9357876

<ul style="list-style-type: none"> • Ireland East Hospital Group • Community Healthcare Dublin South, Kildare & West Wicklow 	<p>Naas Office: 045-920105</p>
<p>Deputy Data Protection Officer South (excluding voluntary hospitals and agencies) Consumer Affairs, HSE South, Ground Floor East, Model Business Park, Model Farm Road, Cork. Eircode: T12 HT02</p> <ul style="list-style-type: none"> • Cork & Kerry Community Healthcare • CHO 5 – Carlow, Kilkenny, South Tipperary, Waterford & Wexford • UL Hospital Group • South South-West Hospital Group 	<p>Email: ddpo.south@hse.ie</p> <p>Phone:</p> <p>Cork Office: 021-4928538</p> <p>Kilkenny Office: 056-7785598</p>

If you are dissatisfied with how we are using your personal data you can contact the DPC.
Phone: 0761 104 800 – Lo-Call: 1890 252 231 - Email: info@dataprotection.ie