

## **Job Description and Person Specification**

### **ERN Data Manager (Grade V Officer)**

#### **Permanent Vacancy**

**Reference: HR25E203**

**Closing Date for Applications: Friday, 29<sup>th</sup> August 2025**  
**In Person Interview Date: Tuesday, 30<sup>th</sup> September 2025**

HR Business Services,  
St Vincent's University Hospital,  
Elm Park,  
Dublin 4.

Contact: +353 (1) 221 6062 or [recruitment@svuh.ie](mailto:recruitment@svuh.ie)

**Job title / Grade:** Rare Disease ERN Data Manager

**Reports to:** The Data Manager will report to the ERN Clinical Lead/Co Lead on the rare disease programme of work.

**Overview:**

The Rare Disease ERN Data Manager is a critical role that will provide structure and leadership ensuring the accurate recording of clinical information and data across the rare disease ERN service. The Data Manager will be responsible for the collection, validation, analysis and sharing of data to advance research.

The Data Manager will collaborate and work closely with the National Rare Diseases Office for national rare disease surveillance and reporting requirements as well as the provision of ERN service activity levels.

**Key Duties and Responsibilities**

**ERN Data Management and Support**

- Manage all aspects of data management activities, collection, validation, analysis, and data reporting for the rare disease ERN service
- Responsible for data entry into the rare disease database and ERN registry/ERN registries
- Responsible for rare disease database maintenance, ensuring they are linked with the relevant ERN registry
- Support the ERN service to fulfil its contracted requirements on ERN patient registration – recruitment, governance, data management
- Support the Clinical Lead/ Co Lead and Care Coordinator to enrol and register patients on the ERN Clinical Patient Management System (CPMS) – IT Platform for Clinical Consultations to enable clinical experts to collaborate and consult on patients across the ERN network, as required
- Complete the ERN annual monitoring exercise and reporting process in conjunction with the ERN MDT service
- Compile relevant data and documentation to support the Clinical Lead/ Co Lead and Care Coordinator in the ERN 5 yearly evaluation process (AMEQUIS)
- Support the ERN service in the implementation of ORPHAcodes, the rare disease coding system
- Update information on Orphanet (the rare disease information portal) as relevant to the service
- Support clinics & MDT meetings, ensuring all the relevant clinical information is collated for review/discussion and collating decisions from MDTs and patient outcomes
- Ensure data privacy and compliance with data protection laws/regulation, e.g. de-identifying patient data, maintenance of recruitment log and obtaining necessary permissions for data use and ethics approval

**Rare Disease Data Reporting**

- Provision of accurate rare disease data and data reporting to support national reporting and surveillance
- Contribute to a national rare disease registry when established
- Streamlining data collection and analysis procedures to ensure fast access to metrics

### Quality and Improvement

- In collaboration with the Rare Disease Care Coordinator, develop KPIs, outcome measures and a process for monitoring quality of care and measuring service impact and performance
- Participate in risk management where required and identify areas for improvement
- Contribute to the development and implementation of policies and procedures for effective data handling and management

**The above Job Description is not intended to be a comprehensive list of all duties involved and consequently, the post holder may be required to perform other duties as appropriate to the post which may be assigned to him/her from time to time and to contribute to the development of the post while in office. This document must be regarded as an outline of the major areas of accountability at the present time, which will be reviewed and assessed on an on-going basis.**

**The Hospital Structure is currently under review and therefore, reporting relationships may change.**

**Informal Enquiries or Role Specific Enquiries:** Ms Karen Donohoe, Deputy Director of Operations  
[kdonohoe@svhg.ie](mailto:kdonohoe@svhg.ie)

### Person Specification

Factors	Essential	Desirable
<b>Qualifications</b>	<p>Eligible applicants will be those who on the closing date for the competition:</p> <ul style="list-style-type: none"><li>• Have satisfactory experience as a Clerical Officer in the HSE, TUSLA, other statutory health agencies or a body that provides services on behalf of the HSE under Section 38 of the Health Act 2004.</li></ul> <p style="text-align: center;"><b>Or</b></p> <ul style="list-style-type: none"><li>• Have obtained a pass (Grade D) in at least five subjects from the approved list of subjects in the Department of Education Leaving Certificate Examination, including Mathematics and English or Irish<sup>1</sup>. Candidates should have obtained at least Grade C on higher level papers in three subjects in that examination.</li></ul>	<ul style="list-style-type: none"><li>• Qualification in ICT or data analytics or a related field</li></ul>

	<p style="text-align: center;"><b>Or</b></p> <ul style="list-style-type: none"> <li>Have completed a relevant examination at a comparable standard in any equivalent examination in another jurisdiction.</li> </ul> <p style="text-align: center;"><b>Or</b></p> <ul style="list-style-type: none"> <li>Hold a comparable and relevant third level qualification of at least level 6 on the National Qualifications Framework maintained by Qualifications and Quality Ireland, (QQI).</li> </ul> <p><i>Note<sup>1</sup>:</i>  Candidates must achieve a pass in Ordinary or Higher level papers. A pass in a Foundation level paper is not acceptable.  Candidates must have achieved these grades on the Leaving Certificate Established Programme or the Leaving Certificate Vocational programme.  The Leaving Certification Applied Programme does not fulfil the eligibility criteria.</p>	
<b>Experience (length and type)</b>	<ul style="list-style-type: none"> <li>Significant experience in data management and healthcare informatics (or related field) working in a healthcare environment</li> <li>Demonstrate the ability to gather, interpret and manage data using various tools and systems including Power BI and advanced Excel, including Pivot tables</li> <li>Knowledge and experience of gathering and interrogating data using various tools and systems, including advanced Excel</li> <li>Excellent planning and organisational skills, including using computer technology effectively as relevant to the role</li> <li>Experience working in a demanding and challenging multi-disciplinary team environment</li> <li>Experience in a role that has involvement dealing with a variety</li> </ul>	<ul style="list-style-type: none"> <li>Experience in the preparation and submission of registry data</li> <li>Experience in statistical analysis</li> </ul>

	of internal and external stakeholders relevant to the role <ul style="list-style-type: none"> <li>• Experience with Microsoft Office Suite</li> </ul>	
<b>Core Competencies</b>	<ul style="list-style-type: none"> <li>• Knowing the Health Service &amp; How it Works</li> <li>• Delivering Quality &amp; Fairness for Service Users</li> <li>• Planning &amp; Managing Resources</li> <li>• Creating Team Spirit</li> <li>• Being the Communication Channel</li> <li>• Influencing People and Events</li> <li>• Managing Individual Performance</li> <li>• Embracing the Change Agenda</li> </ul>	
<b>Health</b>	Candidates for and any person holding the office must be fully competent and capable of undertaking the duties attached to the office and be in a state of health such as would indicate a reasonable prospect of ability to render regular and efficient service.	
<b>Character</b>	Candidates for and any person holding the office must be of good character.	

### Particulars of Office:

**The appointment is:** Whole-time, Permanent, and Pensionable.

**Panel:** A panel may be formed to fill upcoming permanent, temporary, wholetime and part-time vacancies over the next 6 months.

**Annual Salary:** (as at 01/08/2025), pro rata

1	2	3	4	5	6	7	
€51,718	€53,265	€54,843	€56,456	€58,078	<b>€59,969</b>	<b>€61,866</b>	<b>LSIs</b>

These particulars are subject to change in line with overall public pay policy.

**Candidates should expect to be appointed on the minimum of the salary range and in accordance with the Department of Finance guidelines.**

**Probationary Period:** The appointee shall hold office for a probationary period of six months – The Hospital's Probation and Induction policy will apply.

**Pension Scheme:** The candidate will be entered into one of the Hospital Superannuation Schemes.

**Working Hours:** The person appointed will work a basic 35-hour week. You will be required to work the agreed roster / on call arrangements advised to you by your line manager. Your contracted hours of work are liable to change between the hours of 8am – 8pm over seven days to meet the requirements for the extended day services in accordance with the terms of the Framework Agreement. (Reference HSE HR Circular 003/2009). Flexibility on hours of attendance in response to service needs will be a requirement.

**Annual leave entitlement:** 29 days per annum pro rata each year. Annual leave accrued must be taken within the duration of the contract or calendar year and as agreed between the candidate and the Head of Department.

### Additional Information

#### Confidentiality:

During the course of employment staff may have access to or hear information concerning the medical or personal affairs of patients, students, staff and / or other health service business. Such records and information are strictly confidential and unless acting on the instruction of an authorised officer, such information must not be divulged or discussed except in the performance of normal duty. In addition, records must never be left in such a manner that unauthorised persons can obtain access to them and must be kept in safe custody when no longer required.

#### Hygiene:

During the course of employment staff members are required to ensure that the hospital's hygiene and infection control policies are adhered to at all times. All employees have responsibility to prevent

transmission of infection by adhering to and implementing optimal hand hygiene and adhering to the Hospital's Hygiene processes. Hygiene is a fundamental component of St Vincent's University Hospital's quality system to ensure the safety and well-being of its patients and staff and plays a role in the prevention and control of healthcare associated infection.

### **Policies / Legislation:**

All Hospital policies and procedures form an integral part an employment contract and may be subject to update and revision, from time to time, in consultation with union representatives as appropriate. Employees are required to comply with all hospital policies, procedures (e.g. Dignity at Work, Trust in Care, Computer Usage Policy) and the Hospital's ethical codes of practice.

Employees are required to abide by the hospital's code of behaviour and the code of practice as defined by their relevant professional body.

### **Protected Disclosure Policy:**

See link below for more information on our Protected Disclosure Policy as per the Protected Disclosure (Amendment) Act 2022;

[Protected Disclosures - St. Vincent's University Hospital \(stvincents.ie\)](http://www.stvincents.ie/ProtectedDisclosures)

### **Please note the following:**

- The Hospital Board is not responsible for loss or theft of personal belongings
- Fire orders must be observed and staff must attend the fire lectures periodically
- All accidents within the department must be reported immediately.
- In line with the Safety, Health and Welfare at Work Act (2005), smoking within the Hospital Building is not permitted.
- All staff are advised to avail of Hepatitis B Vaccination with Occupational health
- The use of personal mobile phones is prohibited.
- St. Vincent's University Hospital buildings and grounds are **smoke-free**.

**Application Process:** St. Vincent's University Hospital is an equal opportunities employer and is committed to promoting an environment free from discrimination in accordance with the Employment Equality Acts 1998 and 2004. The Hospital values diversity and recognises the benefits of having a workforce that reflects the community we serve. We are committed to equality of access to positions within the Hospital. All recruitment activity and documentation will encourage applications from all potential candidates without discrimination.

Interested candidates should apply for vacancies of interest by visiting the Hospital Careers pages:

<http://www.stvincents.ie/Home/Careers.html>

- Note the closing date(s) for the submission of on-line applications are specified on the list of vacancies. St. Vincent's University Hospital are not able to accept late applications.
- It is the applicant's responsibility to ensure that they apply well in advance of the closing date.
- Any applications which are still in progress but have not been submitted after the closing date will not be registered by our Web Recruitment System.
- Applications for St. Vincent's University Hospital job vacancies will only be accepted through our Web Recruitment System.
- St. Vincent's University Hospital may only take into account technical issues raised by an applicant if advised to our Human Resources Department prior to the advertised closing date.

**Non-European Economic Area Applicants:** While St. Vincent's University Hospital is an equal opportunities employer, in line with current Department of Jobs, Enterprise and Innovation Employment Permit requirements, applications from non-European Economic Area (EEA) will only be considered in the event that an EEA citizen cannot be found to fill the vacancy. Please note that if you are a NON-EEA applicant and are unable to supply documents (listed on [www.djei.ie](http://www.djei.ie)), you are not entitled to participate in this recruitment competition. This is in accordance with the EU Community Preference Rule. Further information is available at [www.djei.ie](http://www.djei.ie).

**Former Public Service employees:** Eligibility to compete may be affected where applicants were formerly employed by the Irish Public Service and previously availed of an Irish Public Service Scheme including:

- Incentivised Scheme for Early Retirement (ISER)
- Department of Health and Children Circular (7/2010)
- Collective Agreement: Redundancy Payments to Public Servants

Applicants should ensure that they are not precluded from re-engagement in the Irish Public Service under the terms of such Schemes. This is a non-exhaustive list and any queries should be directed to an applicant's former Irish Public Service Employer in the first instance.

**Persons in receipt of a pension from specified Superannuation Schemes:** Former Health Service and Public Sector Employees must adhere to the relevant prohibition of re-employment provisions where they have previously availed of a Public Service Voluntary Early Retirement or Ill Health Retirement Pension from any of the following Pension schemes:

- Local Government Superannuation Scheme (LGSS)
- Health Service Executive Employee Superannuation Scheme
- Voluntary Hospitals Superannuation Scheme (VHSS Officers/Non Officers)
- Nominated Health Agencies Superannuation Scheme (NHASS)
- Other Public Service Superannuation Scheme

Among the Voluntary Early Retirement Schemes referred to above are the following:

- Incentivised Scheme of Early Retirement (ISER)
- Voluntary Early Retirement Scheme 2010 (VER)

Prospective candidates must satisfy themselves as to their eligibility to be employed applying / competing for posts to be filled through this recruitment campaign.

**Abatement of Pension (Section 52 of Public Service Pensions Act 2012):** Where a person who is in receipt of a Public Service Pension (e.g. retired on voluntary age grounds) is subsequently appointed to another Public Service post, the Abatement of Pension Regulations apply. This means that in a situation where the total of a person's pension combined with their salary from their new post, exceeds the uprated (current) salary of the position from which they retired, his/her pension is reduced by any such excess amount. This provision applies irrespective of whether the relevant pension was accrued in the same Pension Scheme which applies to the new appointment, or in another Public Service Pension Scheme.



**Shortlisting:** Shortlisting will be carried out on the basis of information supplied on your curriculum vitae. The criteria for shortlisting are based on the requirements of the post as outlined in the Person Specification. Failure to include information regarding these requirements on your CV may result in you not being called forward to the next state of the recruitment process.

All overseas qualifications must be validated. No candidate can work in the Hospital without validated qualifications. If professional registration is also a requirement, candidates must provide documentation of same.

Canvassing will automatically disqualify.

Please note that you will be contacted mainly by mobile phone and email. It is important that your mobile phone number, postal address and email address are correct. It is your responsibility to ensure that you have access to your mobile voice mails and emails. We recommend that you use an email address that you have regular access to.

Competency based interviews follow the shortlisting stage of the recruitment process. Credit is awarded by the interview panel to candidates who demonstrate at interview that they possess the experience, competencies and skills listed in the person specification. Candidates will normally be given at least one week's notice of interview. All interviews are held in person unless it is specifically noted otherwise in the Job Description. No subsequent or alternative dates to dates given will be offered to candidates. All posts are located in St. Vincent's University Hospital, Elm Park, Dublin 4 unless it is specifically noted otherwise in the Job Description.

**Disability:** Please let us know if you need any special assistance at interview, e.g. if you have difficulty in moving up or down stairs or have hearing or speech difficulties.

Candidates are notified of the result of their interview at the earliest possible date after the interview. The recommendation of the interview panel does not constitute a job offer. The process continues after the interview and includes clearance checks such as references, Garda clearance, overseas police clearance (if applicable)\*, occupational health clearance, validation of qualifications and experience. A job offer is made pending satisfactory clearances. SVUH reserves the right to remove candidates from specific recruitment panels and retract job offers if satisfactory clearances cannot be obtained or are deemed unsatisfactory.

*\* If you lived in any country for 6 months or more from the date of your 16th birthday other than the Republic of Ireland or Northern Ireland you will be required to provide security clearance for each jurisdiction in which you have resided. Your security clearance must be dated AFTER you left that country and cover the entire period of your residence. Seeking security clearances from other countries are the responsibility of the candidate. It is a process which can take an amount of time. Therefore we would strongly advise that you commence seeking international security clearances now.*

For some recruitment competitions a panel of successful candidates may be formed as a result of the interviews. Candidates who obtain a place on the panel may, (within the life of the panel), be considered for subsequent approved vacancies. Candidates are placed on a panel in order of merit. A panel is typically live for 6 months.

It is normal procedure that candidates be placed on the first point of the relevant salary scale in accordance with the Department of Finance guidelines.

**Declaration:** Please read your application carefully and check for any errors or omissions. False declaration or omission in support of your application will disqualify you from appointment.

**This document must be regarded as an outline of the major areas of accountability at the present time, which will be reviewed and assessed on an on-going basis.**

**Date: August 2025**