



Feidhmeannacht na Seirbhíse Sláinte  
Health Service Executive

9<sup>th</sup> July 2020

Deputy Róisín Shortall  
Dáil Éireann  
Leinster House  
Dublin 2.

Rannan na nOspideil Ghearmhíochaine  
Aonad 4A – Áras Dargan  
An Ceantar Theas  
An Bothar Mileata  
Cill Mhaighneann  
BÁC 8

Acute Operations  
Health Service Executive  
Unit 4A - The Dargan Building  
Heuston South Quarter  
Military Road  
Kilmainham  
Dublin 8.

**PQ 12389/20** \* *To ask the Minister for Health the number of patients whose genomic data has been shared with a company (details supplied) without consent; when data subject access requests to Irish hospital groups regarding this matter will be processed; and the reason they have not been processed within the statutory one-month time limit*

*Details Supplied: Genomics Medicine Ireland*

Dear Deputy Shortall,

The Health Service Executive has been requested to reply directly to you in the context of the above Parliamentary Question, which you submitted to the Minister for Health for response.

We have asked each Hospital Group to provide an update in relation this matter and we are still waiting for some of them to respond. Please see below the responses we have received to date.

### **Saolta Hospital Group**

Saolta Hospital Group have advised that currently Galway University Hospitals and Portiuncula University Hospital are undertaking research studies relating to the named company, details of which can be supplied if necessary.

There is full ethical approval and patient consent for these studies and all appropriate contractual arrangements are in place.

Saolta also state that to their knowledge NO data has been shared without explicit consent.

Regarding the second point, Saolta Hospital Group state that they do not have any outstanding data requests. They also state that this PQ is not relevant to the remaining hospitals in the Saolta Group.

## **University of Limerick Hospital Group**

The University of Limerick Hospital Group have confirmed that no patient data has been shared with Genomics Ireland without full patient consent. They have also confirmed that University of Limerick Hospitals Group Information Governance Department have not received any data subject access requests regarding this matter.

## **Dublin Midlands Hospital Group**

St James Hospital, Tallaght University Hospital and St Luke's Radiation and Oncology Network will only share genomic data for GMI studies with explicit consent from the patient.

Research projects can only proceed following a comprehensive ethical, legal/governance and data protection review. Hospitals engage throughout the research process to make sure the patient information leaflet is completely explicit with regard to the ownership and transfer of data.

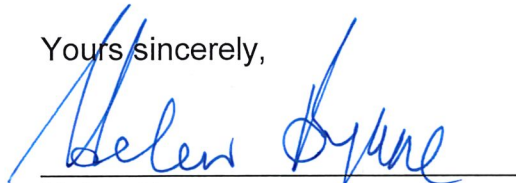
The remaining hospitals in the group, Midland Regional Hospital Portlaoise, Naas General Hospital and Midland Regional Hospital Tullamore have advised that they do not engage with GMI.

We are still awaiting responses from Ireland East Hospital Group, RCSI Hospital Group, South-South West Hospital Group and Children's Health Ireland and we will revert to the Deputy when these responses are received.

To note Ireland East Hospital Group have stated that as of yet none of their hospitals share patient's genomics information with a third party without their consent. Just also to note that The Coombe Women and Infant's University Hospital have come back to us directly to state that they have no engagement with Genomics Ireland.

I trust that this is of assistance

Yours sincerely,



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**Helen Byrne**  
**Assistant National Director, Acute Operations**