



Ref: PQ 16529/25

29th April 2025

Deputy David Cullinane
Dáil Eireann
Dublin 2

Dear Deputy Cullinane

I refer to your parliamentary question below which has been forwarded to me for attention.

PQ 16529/25 – To ask the Minister for Health the reason CHI has removed the spine register, which previously served as an early warning system for new techniques such as vertebral body tethering; and the alternative measures in place to monitor scoliosis surgery outcomes.

Children's Health Ireland (CHI) Response:

While the spine register is no longer online, it is still held by Children's Health Ireland (CHI) as a data controller. CHI stores all personal data that it processes as described in the CHI Privacy Notice available on the website. Strict access controls for the register are in place at all times, alongside all other standard controls as listed in the privacy statement.

Where there is a fundamental change in the processing of the personal data held on the registry, participants will be duly informed in accordance with their rights and CHI's legal obligations under the applicable data protection legislation. The information leaflet provides the necessary information on the registry. It continues to apply.

Families and patients that have participated have the right to revoke their consent at any time via submitting such a request to spine.register@childrenshealthireland.ie and/or DPO@childrenshealthireland.ie

Yours sincerely

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Children's Health Ireland at Connolly | Crumlin | Tallaght | Temple Street

Our Mission is to: Promote and provide child-centred, research-led and learning informed healthcare, to the highest standards of safety and excellence. We will do this in partnership with each other, with children, young people and their families through a network of children's services in Ireland.

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