(English version)

Question for written answer E-002290/25
to the Commission
Nikolaos Anadiotis (NI)
(6 June 2025)

Subject: DNA handed over to US companies: bioethics and anti-democratic screening

According to reports by investigative group Reporters United ([1]), on 17 May 2024, the Greek Minister of Health — without prior consultation with scientific bodies — signed a programme contract for the so-called 'First Steps' project with US biotechnology companies Real Genix and Beginnings ([2]). From 1 January 2025 to 1 March 2029, this 'project' will see maternity hospitals handing over blood samples of 100 000 newborns to these companies for DNA analysis, with them even being granted exclusive ownership of the research results.

Collaborating in such a large-scale neonatal genetic screening exercise — and putting the babies' data on file for life — raises serious moral and ethical problems and puts their most sensitive personal data at risk. Moreover, the Greek Child Health Institute has stated that there is currently no valid informed consent from parents for the performance of mass diagnostic testing of this kind, while there have also been reactions from many scientists ([3]) ([4]).

In light of the above, can the Commission say:

1. In its opinion, is it lawful and ethical for the Ministry to send neonatal genetic material for comprehensive genetic screening without parents being informed or granting their consent?

2. Is it aware of generalised genetic screening programmes being implemented by any other Member States?

3. Does it know how many samples have been sent to the US since 1 January 2025?

Submitted: 6.6.2025

Answer given by Mr McGrath on behalf of the European Commission
(22 September 2025)

Articles 1 and 3 of the EU Charter of Fundamental Rights ([1]) protect human dignity and any person's right to integrity, including for newborns, requiring free, informed consent for medical and biological procedures, with the Charter applying to EU institutions and national authorities only when they are implementing EU law.

The Council of Europe's Oviedo Convention ([2]), ratified by Greece, further requires that medical interventions on minors unable to consent must be authorised by a legal representative or a designated authority.

Processing of personal data in the scope of the General Data Protection Regulation (GDPR) ([3]) — among other requirements — requires a legal basis, such as a law assigning a task in the public interest for the performance of which the processing is necessary, or the consent of the data subject. The controller must also inform the data subjects about the processing under the rules of the GDPR.

The monitoring and enforcement of the application of the GDPR falls within the competence of the national authorities and courts, without prejudice to the competences of the Commission as guardian of the Treaties.

The Commission does not assess individual cases of compliance with the GDPR, nor conduct investigations into such matters. Regarding processing carried out by or on behalf of Greek public sector bodies, this falls into the competence of the Greek Data Protection Authority ([4]).

Regarding the second and third questions, the Commission has neither detailed information about Member States' general screening programmes for newborns using full genome sequencing, nor any details about samples being sent to the United States referred to by the Honourable Member.

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1 [1]https://www.reportersunited.gr/16145/adonis-georgiadis-dna/
2 [2]https://www.documentcloud.org/documents/25893844-programmatike-sumbase-up-ugeias-me-realgenix-beginnings/
3 [3]https://ygeianet.gr/epistoli-195-epistimonon-gia-ti-diathesi-dna-neognon-se-xenes-etaireies-2/
4 [4]https://www.tovima.gr/2025/05/21/health/o-adonis-to-gonidioma-kai-ta-prosopika-dedomena/
([1]) https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:12012P/TXT.
([2]) https://rm.coe.int/168007cf98.
([3]) Regulation (EU) 2016/679 of the European Parliament and of the Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC, OJ L 119 4.5.2016, p. 1.
([4]) https://www.dpa.gr/.