

## In search of our origins: regulating open-access *genetic testing*

CATHERINE PAJARES Y SANCHEZ AND MARTINE VIGNAU

In France, the use of genetic testing for personal or private purposes is strictly prohibited outside the context of legal proceedings or a medical prescription. The law provides for a criminal penalty of up to a €3,750 fine for those who request such tests. However, this general ban is now coming into direct conflict with the reality of how such tests are actually used. The fundamental need to know one's origins, particularly acute among people born to anonymous donors, those who were adopted, or those conceived through assisted reproductive technology (ART) with a third-party donor, is driving many citizens to circumvent the law.

The gap between the law and practice has become massive. Every year, between 100,000 and 150,000 French people order saliva kits from foreign platforms. It is estimated that to date, 1.5 to 2 million of our fellow citizens have already chosen to act illegally in order to trace their personal history. In the face of this widespread circumvention, criminal penalties are never enforced, revealing the total ineffectiveness of national law.

This regulatory vacuum creates significant legal and health uncertainty. By maintaining this ban, the State is leaving the field open to a globalised DNA market, dominated by non-European companies. The most private genetic data of French citizens is thus exported outside the European Union, evading the safeguards of the General Data Protection Regulation (GDPR). This loss of sovereignty exposes the population to risks of commercial exploitation of their biological heritage and to data trafficking already documented on clandestine networks. Faced with this impasse, the EESC proposes moving beyond the illusion of a ban to build a truly protective European and national framework.

**3750**  
euros

This is the amount of the fine provided for by law for carrying out a private genetic test.

**between  
1.5 and 2  
million**

French people have already taken part in genetic tests for genealogical purposes.

**1** DECriminalISING GENETIC TESTING

- **How?** By permitting the purchase of DNA tests strictly for family purposes (whilst maintaining the criminal prohibition on medical and ethnic testing).
- **Why?** To put an end to the hypocrisy that criminalises 1.5 million French people seeking to trace their roots, and to finally allow for genuine public oversight of these practices.

**2** CREATING A EUROPEAN SHIELD FOR OUR DATA

- **How?** By requiring DNA data to be stored on European servers, under the supervision of a new European certification agency.
- **Why?** To put a stop to the mass export of our biological heritage and ensure compliance with the GDPR in the face of the opaque non-European market.

**3** PREPARING PROFESSIONALS FOR THE 'CULTURE SHOCK'

- **How?** By providing specific training for healthcare and social care professionals (doctors, psychologists, support workers, etc.) in interpreting test results and providing psychological support.
- **Why?** So that citizens are no longer left to face, alone behind a screen, the sudden revelation of family secrets or previously unknown half-siblings.

**4** MAKING THE STATE A TRUSTED THIRD PARTY

- **How?** By significantly increasing the resources available to public bodies (CNAOP, CAPADD) dedicated to people born under the 'X' designation or born as a result of gamete donation.
- **Why?** To provide a single, secure point of contact, thereby preventing the citizens concerned from turning to private companies out of frustration.

**5** PROTECTING THE SOCIAL SECURITY BUDGET

- **How?** By ensuring that the cost of genealogy tests remains solely the responsibility of applicants (no reimbursement from the National Health Service).
- **Why?** To ensure that funds from the national solidarity scheme are used exclusively for medical treatment and the care of those with serious illnesses.

**6** EDUCATING AGAINST THE ILLUSIONS OF THE DNA

- **How?** By incorporating the key issues of genetics and bioethics directly into the school curriculum.
- **Why?** To equip young people to deal with misleading marketing by online platforms and prevent extremist ideologies based on a misinterpretation of science.

**THE RAPORTEURS**

**Catherine Pajares y Sanchez**  
 catherine.pajares@lecese.fr  
 (33)1 44 43 64 07

Catherine Pajares Y Sanchez, a policy officer at the CFDT trade union confederation, chairs the CFDT group within the EESC and sits on the Committees on European and International Affairs, Social Affairs and Health, and the temporary committees on 'Cannabis' and 'Cross-cutting Opinions'.

**Martine Vignau**  
 martine.vignau@lecese.fr  
 (33)1 44 43 64 24

Martine Vignau, UNSA's National Secretary for the social sector, sits on the Advisory Council for People with Disabilities (CNCPH). As Vice-President of the CESE responsible for parliamentary relations, she chairs the UNSA group and has been a member of the Standing Committee on Social Affairs and Health since 2015. She also served on the governance committee of the Citizens' Convention on 'Children's Time'.