

PICUM BRIEFING

DATA PROTECTION AND THE "FIREWALL": ADVANCING THE RIGHT TO HEALTH FOR PEOPLE IN AN IRREGULAR SITUATION



Modern information technology and the age of Big Data have dramatically increased the likelihood of misuse of individuals' personal data. Recognising this, on 25 May 2018, the EU adopted the General Data Protection Regulation (GDPR), a powerful new legislative framework that reinforces everyone's right to the protection of their personal data by improving transparency and accountability in the processing of personal data and strengthening individuals' control over how their data is used.

The GDPR has particular relevance for migrants' rights given the growing large-scale use of data processing to enhance migration control and policing.¹

This factsheet explains the relationship between the GDPR and the concept of the "firewall", a tool to safeguard the fundamental rights - including the right to health - of people in an irregular situation in Europe.

THE "FIREWALL" SAFEGUARDS FUNDAMENTAL RIGHTS, INCLUDING THE RIGHT TO HEALTH

"Firewalls" are built on the premise that while states have the prerogative to enforce immigration laws, they also have obligations to protect fundamental rights. Those fundamental rights include the right to health. A "firewall" delinks the delivery of health care from the enforcement of immigration rules, ensuring that public trust and the pursuit of important social and health goals are not undermined or interfered with by political objectives on migration control.

Under international human rights law, states have a duty to ensure the right to health, among other things by taking concrete steps towards realizing universal health care, as well as the preconditions for health. These measures must be pursued in a way that does not discriminate based on residence status. States also have a duty to *refrain* from doing certain things that undermine the right to health. The UN committee that oversees states' progress in meeting their obligations in the realization of economic and social rights has described³ several examples of how a state can fail in this duty to respect the right to health:

- > "denial of access to health facilities, goods and services to particular individuals or groups";
- > "adoption of laws or policies that interfere with the enjoyment of the any of the components of the right to health"
- "failure of the State to take into account its obligations" regarding the right to health when entering into bilateral or multilateral agreement with other States, international organizations and other entities".

- 3 UN Committee on Economic, Social and Cultural Rights, General Comment No. 14: The Right to the Highest Attainable Standard of Health (Article 12).
- 4 Statement by the Committee on Economic, Social and Cultural Rights (13 March 2017), Duties of States towards refugees and migrants under the International Covenant on Economic, Social and Cultural Rights.

Insecure Status Creates Health-Related Vulnerabilities

For people living in Europe with irregular status, being undocumented usually means being shut out from regular job markets, social safety nets, and health systems. A 2019 report² examining evidence from Médecins du Monde clinics providing care to people who fall through the cracks of national health systems in seven European countries found that 92% of patients fell below the poverty line, close to 80% were homeless or lived in a precarious living situation – and 55% were undocumented. This underscores the link between social precarity and precarious residence, and how being undocumented can have a profound and negative impact on mental and physical health, which is exacerbated by extremely limited access to health care in most parts of Europe.

1 Statewatch (2019), Data Protection, Immigration Enforcement and Fundamental Rights: What the EU's Regulations on Interoperability Mean for People with Irregular Status.

2 Medecins du Monde, University College of London (2019), Left Behind: The State of Universal Health Coverage in Europe.

The application of immigration rules must not interfere with the correct application of the human rights obligations of states in respect of all persons in their jurisdiction. ... There must be clear firewalls which separate the activities of state authorities which provide social services and, where applicable, the private sector, from immigration control and enforcement obligations."

Council of Europe, European Commission against Racism and Intolerance (ECRI), General Policy Recommendation No 16

A state's duties under the right to health therefore extends beyond its citizens to everyone within its territory, irrespective of migration status;⁴ and beyond policies and practices within the sphere of health to those that *affect* health.

A person's immigration status is changeable and depends on many factors, particularly a country's rules about the conditions of entry and stay, and how they are enforced in practice. The "firewall" ensures that the protection of a person's fundamental rights is not dependent on the vagaries of their administrative status. The application and enforcement of immigration rules does not need to – indeed, must not – come at the expense of fundamental rights.

Migrants in an irregular situation may also fear being detained for deportation, particularly in countries where public officials have a duty to report on irregular migrants. In addition to ensuring access to health care without discrimination, strict walls should exist between health-care personnel and law enforcement authorities...."

UN Committee on Economic, Social and Cultural Rights, Duties of States towards refugees and migrants under the International Covenant on Economic, Social and Cultural Rights (13 March 2017)

GDPR: PROTECTION OF PERSONAL DATA REINFORCES THE "FIREWALL"

The EU General Data Protection Regulation (GDPR) came into force on 25 May 2018 and sets out clear rules on the processing of personal data that increase the rights of individual data subjects, with the aim of fostering greater transparency and accountability in the use of personal data. The GDPR applies across the European Economic Area (EEA) to the processing of data by private actors, certain authorities, and public service providers. The GDPR should be understand as an effort to strengthen even further fundamental rights to privacy, taking into account advancements in technology and the ease with which personal data can be collected and transmitted today.

Because irregular entry and stay are often criminalised, people who are undocumented face the risk that the use of services will expose them to immigration enforcement. Explicit data-sharing arrangements between health or social services and immigration services exist in some member states,⁵ which has the effect of discouraging health-seeking behaviour and undermining the right to health. Even where such formal arrangements don't exist, there is often no protection against ad hoc incidents of reporting by medical staff or administrators.

The GDPR reaffirms that data protection is a fundamental right under EU law that applies to everyone. The GDPR also reinforces important concepts in the health context, such as medical privacy and confidentiality which are core principles critical to ensure trust in health professionals and in the health system

5 Countries where such arrangements exist including the UK (see Liberty (2019), Care Don't Share: Hostile Environment Data-Sharing: Why We Need a Firewall Between Essential Public Services and Immigration Enforcement) and Germany (see Working Paper of the National Working Group on Health/Illegality (Arbeitspapier der Bundesarbeitsgruppe (BAG) Gesundheit/Illegalität) (April 2017), Healthcare for Undocumented Persons).

The GDPR:

- Imposes strict rules on the use of personal data by public authorities and private actors who are active within the European Economic Area.
- > Further strengthens and implements fundamental human rights to privacy and data protection, and protects individuals' rights without distinction based on nationality, place of residence, or residence status.
- Is grounded in rights already well-established under the EU Charter of Fundamental Rights (Articles 7 and 8) and the European Convention on Human Rights (Article 8), born out of atrocities committed during WWII and privacy right infringements during the Cold War, and responds to concerns about new technology and the potential encroachment of big data on those rights.
- In most cases, forbids the sharing, transfer or exchange of personal data between service providers and immigration authorities for enforcement purposes as contrary to the bedrock principles of privacy and data protection.

The GDPR establishes several key Principles for the lawful processing of data.

> Purpose limitation

The GDPR sets strict limits on the reasons for which data can be processed.

The principle of "purpose limitation" is a cornerstone of the GDPR, and of data protection rights under the European Court of Human Rights. It requires that personal data be collected for a specified, explicit and legitimate purpose, and not be further processed in a way incompatible with this purpose.

If information is originally collected by service providers for the provision of health care, its transfer to immigration enforcement authorities will generally be incompatible with the initial purposes for the processing – particularly given the private nature of the data and the potential far-reaching negative impact on an already vulnerable population of data subjects.

> Data minimization

The GDPR prohibits processing of personal data beyond what is strictly needed to achieve the purpose for which the data was initially collected.

The principle of "data minimization" requires that personal data gathered must be adequate, relevant and limited to what is necessary in relation to the purpose for which it is collected.

Processing information about an individual's immigration status will generally not be necessary for the purpose of providing public services like health care, education, or social services. Where it might be needed, for instance to verify eligibility for reimbursement of health costs, the purpose limitation must be respected.

> Sensitive data

The GDPR provides enhanced protection for sensitive data. This includes data revealing racial or ethnic origin, data concerning health.

Such data, which can also include personal data concerning sex life or sexual orientation, and, in some cases, biometric or genetic data, should generally only be processed with the consent of the person or, in exceptional circumstances, when necessary for reasons of substantial public interest under national or EU law.

Exceptions to the GDPR are narrow, recognising that data protection and privacy rights are fundamental rights.

Governments can only deviate from the GDPR based on clear EU or national legislation that: (i) respects the fundamental rights and freedoms of individuals who would be affected by the exception; (ii); safeguards a specific and pressing social need (such as national security, the prevention, investigation, detection or prosecution of criminal offences or other important objectives of general public interest); (iii) is sufficiently clear and precise to be foreseeable to affected individuals; and (iv) is necessary and proportionate in a democratic society.

There is a strong case to make that immigration enforcement that interferes with access to essential services, such as health care, is unlikely to meet this high threshold.

RESOURCES

- Committee on Economic, Social and Cultural Rights, <u>Duties of States towards refugees and migrants under the</u> <u>International Covenant on Economic, Social and Cultural Rights</u>, 13 March 2017, E/C.12/2017/1
- Council of Europe, European Commission against Racism and Intolerance (March 2016), <u>ECRI General Policy</u> <u>Recommendation No. 16 – On Safeguarding Irregularly Present Migrants from Discrimination</u>.
- Liberty (2019), <u>Care Don't Share: Hostile Environment Data-Sharing: Why We Need a Firewall Between Essential</u> <u>Public Services and Immigration Enforcement</u>.
- Medecins du Monde, University College of London (2019), Left Behind: The State of Universal Health Coverage in Europe.
- PICUM (2016), <u>The Sexual and Reproductive Health Rights of Undocumented Migrants: Narrowing the Gap between their Rights and the Reality in the EU</u>.
- Regulation (EU) 2016/679 of the European Parliament and 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 (General Data Protection Regulation)

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