

Mandate of the Special Rapporteur on the right to privacy

REFERENCE:
OL OTH 56/2019

28 November 2019

Dear Sir,

I have the honour to address you in my capacity as Special Rapporteur on the right to privacy, pursuant to Human Rights Council resolution 37/2.

As an independent human rights expert appointed and mandated by the United Nations Human Rights Council to report and advise on the human right to privacy, I am sending to you this letter under the communications procedure of the Special Procedures of the United Nations Human Rights Council to seek clarification on information I have received.¹ Special Procedures mechanisms can intervene directly with Governments and other stakeholders (including companies) on allegations of abuses of human rights that come within their mandates by means of letters, which include urgent appeals, allegation letters, and other communications. The intervention may relate to a human rights violation that has already occurred, is ongoing, or which has a high risk of occurring. The process involves sending a letter to the concerned actors identifying the concerns, the applicable international human rights norms and standards, and questions of the mandate-holder(s), and a request for follow-up action. Communications may deal with individual cases, general patterns and trends of human rights violations, cases affecting a particular group or community, or the content of draft or existing legislation, policy or practice considered not to be fully compatible with international human rights standards.

In this connection, I would like to bring to your attention information I have received concerning ‘Project Nightingale’, an initiative reportedly between Google and Ascension to gather the health data of patients across 21 American States. Some of this coverage has raised issues such as lawful privacy protections and appropriate practices.

While digital health technologies, including health related databases, can offer improved health outcomes, cost containment and better services, an integral part of capturing these benefits is patients’ and citizens’ trust in the use of such technologies. Much of this trust depends upon the responsible and transparent management of their health data according to established data protection protocols and privacy standards.

Recently, I presented to the United Nations General Assembly my ‘Recommendation on the protection and use of health-related data’² (hereinafter the “Recommendation”) which provides guiding principles for the processing of health-related data. This Recommendation serves as an international baseline for minimum data protection standards for health-related data. It has been developed by the Health Data

¹ Further information about the communication procedure is available at:
<http://www.ohchr.org/EN/HRBodies/SP/Pages/Communications.aspx>

² <https://undocs.org/A/74/277>

Privacy Thematic Taskforce established by and under my mandate, and is the product of extensive international consultations, including with American data and health experts, as well as civil society, human rights and other advocacy bodies.

The Recommendation is premised on the principle of international human rights law that everyone has the right to the highest attainable standard of physical and mental health, and to the highest attainable standard of protection for their health-related data regardless of origin, disability, gender, age, amongst other factors. The Recommendation includes strong protections for health data, with provision for uses of health data for reasons of public interest such as for scientific research.

The right to health and quality healthcare have an important foundation in the protection of the right to privacy. Frequently overlooked matters such as poorly managed health related data in Electronic Health Records, healthcare record keeping, IT systems, and databases amongst other things, undermine the confidence of the patient, their families and the public at large in health care systems.

Initiatives such as the reported ‘Project Nightingale’ have the potential to impact upon the lives of millions of citizens and others, well into the future. Accordingly, I welcome information on the development of any such initiatives, and the consideration in this context of the attached “Recommendation on the protection and use of health-related data” and the accompanying “Explanatory Memorandum”.

I thus respectfully recommend to give full consideration to these guidelines outlined in this framework, with the view to disseminate and adopt them to the extent possible so as to ensure that health data are managed within a proper normative framework consistent with the commitment of the United States Government to promote and protect the universal right to health and the not less fundamental right to privacy in the processing of health related data

I would appreciate receiving a response within 60 days. Passed this delay, this communication and any response received from your part will be made public via the communications reporting [website](#). They will also subsequently be made available in the usual report to be presented to the Human Rights Council.

Please accept the assurances of my highest consideration.

Joseph Cannataci
Special Rapporteur on the right to privacy