



## **USE YOUR 'RIGHT TO KNOW' IN IRAN TO FIND OUT ABOUT HEALTH ISSUES**

Under Iranian law, you have a right to know about issues and decisions made that affect you and your community's health.



June 2020

#### Your rights to health-related information

According to Article 29 of the Iranian Constitution, the government is responsible for providing physical, psychological, spiritual and social health for people. Achieving these can be enabled by the right to access information; which supports individuals to demand their health rights.

Under Iran's Free Publication and Free Access to Information Act, you have a right to request information from public and many private institutions, who must deliver except in limited situations. Requests could include information about the activities and decisions of public officials, Ministry of Health budgets, and local and government projects. In this guide, you can find links to our resources to help you better understand the law and how to use it.

Under the Patients' Rights Charter, you also have a right to obtain your health records held by hospitals, doctors and other health care officials. Hospitals and clinics must also publish information about their activities. Your records are subject to strict confidentiality.



### IRAN'S PUBLICATION AND FREE ACCESS TO INFORMATION ACT



#### Who can ask for information?

All Iranian citizens and legal entities have the right to access information under Iran's Publication and Free Access to Information Act. This means that people such as journalists, health experts, academics, activists, and concerned citizens can all make information requests.





#### What kind of information can you ask for?

You can ask for **any kind of information held by public institutions** such as contracts, budgets, agreements, published and unpublished reports, emails, hospital datasets, or project outlines. This can also be your own personal information held by government institutions, such as medical files. The information can be in any form including written documents, audiovisual files, images, electronic records, and data in any physical or electronic form, so long as it has been recorded.

# Do you need to show a legal reason to obtain information?

**No. The law does not require you to provide a legal reason to make a request.** So you do not have to show that you will be directly affected by a project or health hazards. In fact, Article 7 of the Act prohibits public institutions from asking requesters to "provide a reason or explanation for their request."



#### Institutions covered under the Act

The Act applies to all public bodies in the executive, legislative and judicial branches and their affiliated bodies and subsidiaries, as well as provincial governments and municipalities. It also applies to private bodies including companies and NGOs which provide public services. However, there are limitations to its application to bodies under the direct control of the Supreme Leader (under Article 10 of the Act).





THE RIGHT TO INFORMATION

ARE CONNECTED

AND THE RIGHT TO HEALTH

### HOW CAN THE ACT HELP HEALTH-RELATED ISSUES?

#### The rights to information and health are inextricably connected.

Iran's access to information law enables citizens to access information on how public officials are spending money, operating services and making decisions. Taking advantage of this right can help hold government authorities and affiliated bodies and subsidiaries accountable for work or projects that affect health as well as pushing to have more done to protect your health related rights.

For example, making information request about the government's plans around womens' health. Scenarios could include:

- The availability of medicines and treatments in your local clinic;
- How much funding has been assigned by the Bureau for Population Health to educational materials on menstruation in your city between 2018 and 2019; or
- How many government funded staff were allocated to the maternity ward in your town each year from 2015 to 2018.

The potential topics for information requests are unlimited. Hospitals and clinics must also publish information about their activities.

You also have a right to obtain your own health records held by hospitals, doctors and other health care officials. Further, your records are subject to strict confidentiality so other people cannot access your records.

#### How to make a request

There are multiple ways to file a request. The Ministry of Communication and Information Technology operates an **online portal (<u>http://foia.iran.gov.ir</u>)** for making and receiving requests, and filing appeals. The online portal is intended to be the standard platform for requesters to request information, and is already being linked to by many public bodies - including the Ministry of Health and its local bodies.

In addition, you can make requests by:

- Submitting a form online via the institution's website (or other electronic gateway) if not through the MCIT portal);
- By post; or
- Applying in person to the Information Unit of the institution.

You are required to provide information about yourself in the request including your name, national ID number or national registration number (for legal entities), address, and an Iranian phone number. For the Government e-service, you must register using your national ID number. INFORMATION REQUESTS CAN HELP KEEP GOVERNMENT & HEALTH AUTHORITIES ACCOUNTABLE







http://foia.iran.gov.ir

#### How long must you wait to get the information?

**Public and private institutions are required to respond to requests within ten business days.** Bodies are required to consider the "nature, urgency, and necessity" of the request in determining how quickly to respond, so may respond quicker.

Public institutions must immediately "provide a written or electronically issued receipt which includes registration date and number to the applicant". The request can be tracked using the online portal.

INSTITUTIONS MUST RESPOND

IN 10 BUSINESS DAYS

Institutions must respond in one of four ways, chosen by the requestor:

- Online through the applicant's internal email address;
- Online through the applicant's Iranian national file reference;
- In written form, by post, to the address and postal code provided by the applicant; or
- In written form, in person.

Fees

# Information access should be granted for free. But some information requests may involve fees.

Executive agencies can collect revenues generated by sales of publications and software to cover service costs if the Commission has approved such tariffs. Other institutions are also authorised to charge for their services. However, to date most requests have incurred no fees.

# MOST REQUESTS SHOULD NOT INCUR FEES





#### What information can be withheld?

There are seven exemptions in the law under Articles 13-17. (You can read the full text of the law here: <u>https://rc.majlis.ir/fa/law/show/780303</u>)

Information can be withheld if it relates to:

- State secrets (as defined by the 1974 State Secrets Act);
- Protecting personal privacy;
- Protecting health or commercial information;
- Public peace and security;

ACCESS TO INFORMATION

RIGHT TO PRIVACY

MUST BE BALANCED WITH

- Prevention or investigation of crimes or prosecution of criminals;
- Tax audits or legal fees, or their collection; or,
- Monitoring immigration into the country.



The exemptions generally are not absolute. Many require that the institutions show some form of harm to the body or another's interest. If your request is refused, you should ask for a written explanation or documentation.

Importantly, the exemptions do not apply if the information requested would reveal the existence of environmental hazards or public health threats (Article 17, Note 1). This is a very important caveat to keep in mind, if your health request is rejected.

Requests can also be rejected when:

- The request is considered by an institution to be incomplete or insufficient information is provided. A requestor can submit a follow-up request providing the missing information.
- The request is made for documents or information that have been openly published and is accessible through the institution's website.
- The request would release information that causes disgrace and harm to one's reputation, is deemed to be against public decency, and/or is considered to be promoting vice.



## WHAT YOU NEED TO KNOW ABOUT THE BALANCE OF PRIVACY AND ACCESS TO INFORMATION?

The right of access to information must be reconciled with the right to privacy. This is especially important to keep in mind when looking at access to information and health and understanding the boundaries. As we see above, under Article 14 of the Publication and Free Access to Information Act, information relating to privacy or personal data can be withheld when it would harm the person's interest - however this exemption is not absolute. The wording under this article is quite broad, so in practice certain requests may be assessed differently depending on their link to public interest. For example, privacy rights might apply differently to names of officials and their official activities. This will depend on how well the request demonstrates the public interest linked to the information. It must be noted that the right of privacy should not apply to anonymised or statistical records, such as the number of people impacted in an area by an illness such as a virus.

Iran's health laws provide for confidentiality of patients' data. The Patient Rights' Charter of 2009 aims to make patients aware of their own rights and can be used by patients for them to decide about their own health. Among its most important sections relevant to access to information and privacy are:

- Provision of health services should be based on respect for the patient's privacy and observance of the principle of confidentiality; and,
- Observing the principle of confidentiality is necessary for all information related to the patient, except in cases where the law has posed an exception.

Under Iranian law, confidentiality is among the legal aspects of medical documents. In all stages of care, including diagnosis and treatment, the patient's privacy should be respected. It is thus necessary for all necessary facilities for guarantee of the patient's privacy to be provided.

## The instructions firmly state that Patient information is completely confidential and can only be used by written permission.

In addition, Iran's laws including Article 648 of the Islamic Penal Code, set out heavy penalties that medical professionals face if they reveal any private information outside the constructs of the law.

So, keep in mind that there are strict laws in Iran about privacy and personal patient data. Understand what data you can demand and what you cannot. But remember that this does not affect your right to access your own medical information.

There are caveats to this. Based on instructions by the health ministry, patient secrets should only be divulged in cases where it is necessary to prevent damage and should only be shared with those who need to know about it to prevent damage. The instructions require that this be done with minimum of damage and suffering to the patient. For example in the case of the spread or the threat of the spreading of a particular disease information sharing should be done without the name of the patient or specific information of the patient, as here public interest takes priority over the rights of the individual.

### CLINICAL INFORMATION BETWEEN DOCTOR & PATIENT REMAINS CONFIDENTIAL







#### What if you are denied your request for information?

If a request for information is denied, the institution must communicate to the requestor the legal reasons for denial.

You can appeal. If you believe that your request has been denied unlawfully, you can appeal to the Commission for Publication and Free Access to Information in the Ministry of Culture and Islamic Guidance. Complaints can be filed through the government E-service or directly with the Commission.

> Secretariat telephone: 88714843 Fax: 88715316 Email: commission@iran.ir

 $\int$ 

Appeals of denials can also be made to a court. According to the Iranian Constitution, a complaint against a government institution, including the Information Commission, can be made to the High Administrative Tribunal in Iran. The complaint can be submitted in person or through the Judiciary platform at: <u>http://www.adliran.ir/</u>. This website also gives instructions for making appeals to the Administrative Tribunal: https://divan-edalat.ir/show.php?page=documents

### WHAT DO IRAN'S HEALTH LAWS SAY ABOUT ACCESS TO INFORMATION?

There are also other legal rights to be able to obtain healthrelated information. Based on an instruction by the health ministry, patients can access their personal information and can request to correct the information in their medical document. Iran passed a number of laws granting patients access rights. These include provisions that set out:

- The patient's right to their own medical files and the right to access the information in them. To access the file, the patient should make a written request. Those above 18 years old can fill out a request form (for example from this portal: <u>http://sib.arums.ac.ir</u>) and get a copy of their medical file. Giving access to a patient's file to relatives can only happen if you have a consent form from the patient. In the case of patients under 18 or those who are not fully conscious (in coma, mental health patients, etc.), their guardian or legal representative can get a copy upon filling a request form. If the patient passes away, the inheritor can get a copy.
- Importantly this copy of the medical file is to be given for free.
- Employers can only access medical files of a patient with the written permission/consent of the patient.

THERE ARE A NUMBER OF LAWS GRANTING PATIENT ACCESS RIGHTS



There are other provisions in Iran that support the notion of access to information for health. For example, the Patient's Rights Charter firmly outlines that patients must have access to all information registered in their hospital case and get a copy of it and demand correction of the mistakes therein.

You also have the **Sepas Plan (Sepas is a Persian acronym for "Electronic Health File System").** This is based on the existing policies on creation of electronic health files in Iran. Under this plan, it is necessary for the patient to have access to or request access to their own electronic file to be reviewed. According to government announcements, every Iranian has an electronic health record that will be identified and numbered with their national ID number. According to the layout and announcements, non-nationals residing in Iran will also be able to use the system.

You can find the portal and sign up for it here via the "Seeb Portal": <u>http://sib.arums.ac.ir</u>

People also have the right to control their own confidential health information (by permission or consent.) However, there are legal exceptions to this. They include general health monitoring (for example in following up on infectious diseases) and particular research health needs such as epidemiological studies which need a large population whose files will be used under the supervision of an official review board tasked with safeguarding privacy.

# What can you do when you receive requested information?

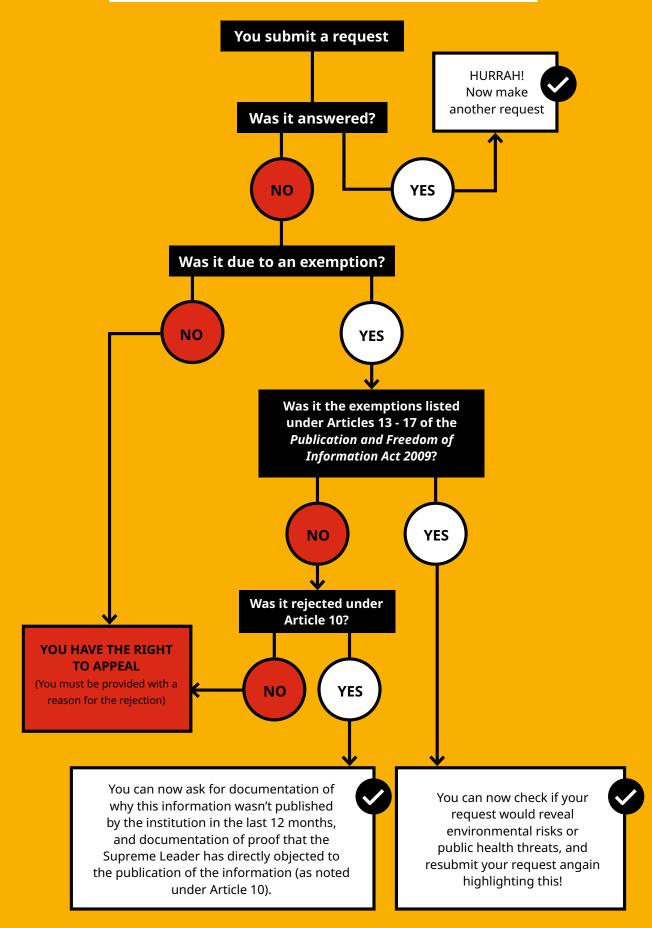
The information you receive is public information. Based on broader international law, you can use such information. However, the Act does not outline the procedures around the reuse or republication of obtained information. For your protection, be mindful of the type of request you make, who you make the request to and how you use the information. Remember, your own personal medical files are not public, unless you choose to make them so.



# What happens if institutions refuse to give you the information you are entitled to?

Article 22 of the Act provides civil penalties for deliberate violation of its requirements by public bodies, including restricting access to information contrary to the law, erasing or modifying information, and violating deadlines. The penalties range from 300,000 rials up to 100,000,000 rials. This is something you can ask the Information Commission to enforce.

## WHAT OPTIONS DO YOU HAVE IF YOUR REQUEST IS REJECTED?





### DUTY TO PUBLISH

In addition to the rights of citizens to be able to demand information from bodies, there are also legal requirements that the bodies regularly publish information about their activities.

Under the Publication and Free Access to Information Act, public and private institutions are also required to proactively publish information about their activities without receiving a request. This includes information on their:

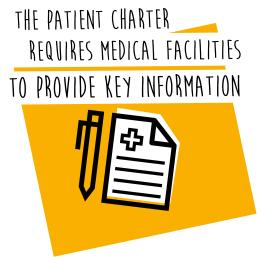
- Legal duties and obligations;
- Laws and regulations governing the activities of the institution;
- Organisational chart, and responsibilities of every position within the institution to the most junior level;
- Complete list of the directors;
- List of all subsidiary and superior entities, and ways to access them;
- A page to allow voicing objections to the activities of the institution; and,
- Notice of auctions and tenders, and their latest updates.

A full list of information that institutions are required to publish is available in the 2014 executive bylaw.

Under Note 1 of Article 10 of the Act, there is a caveat that states organs under the direct control of the Supreme Leader are not required to publish information if there is opposition by the Supreme Leader.

**Do note here:** If you require information that you believe should be proactively published by one of these organs (for instance a military hospital) and has not been, you are entitled to make a request to it and ask for the documentation showing the opposition of the Supreme Leader for its proactive publication.

Other provisions encouraging proactive publication include **the Patient Rights' Charter** which requires medical facilities to provide information to patients. It makes clear that information should be provided to the patients in a suitable fashion and as necessary. It clarifies that the information should consist of the following:



- Content of the Patient Rights' Charter upon registration;
- Regulations and predictable hospital costs including those related to treatment or otherwise and regulations of insurance and introducing supportive systems upon reception;
- Name, responsibility and professional position of the medical team members who provide care, including doctors, nurses, students and their professional relationship with each other;
- Diagnosis and treatment methods and positive and negative points about each method and possible side-effects, diagnosis and prognosis of the disease, its side-effects and all information that can affect the patient's decision-making process;
- Process of accessing a doctor and main members of the medical team during the treatment.

These are all areas of information you should be proactively provided with. The Charter also sets out complaints procedures if the rights under the charter are not met. You should be provided with an efficient follow-up system for complaints. If you make a complaint about your right under the charter being violated by relevant authorities, it must be processed without disruption in receiving of health services; and finally, you have the right to learn about what happens to their complaints and how they were followed up on.



#### More information

#### Find out more at article19.org on:

Laws and regulations affecting access to information The information requests portal Legal analysis on Iran's Freedom of Information Act General guide to making requests in Iran General guide to making requests in Iran for journalists