

Privacy Notice

This notice describes how medical information about you may be used and disclosed and how you can get access to this information. Please read this notice carefully.

We at Dana-Farber Cancer Institute (DFCI) pledge to give you, our patients, the highest-quality health care. But just as important to the mission and goals of Dana-Farber is our belief that every patient and family member deserves to be treated with respect. We encourage you, as a patient or the legal representative of a patient, to play a role in your treatment and care. One way you can do this is by understanding your rights. We are committed to ensuring that these rights are protected.

Your overall rights as a patient are described in Dana-Farber Cancer Institute's *Patient Rights and Responsibilities* document. Many of your rights are also guaranteed under state and federal laws, particularly the Massachusetts law known as the "Patient Bill of Rights" (M.G.L., ch. 111, sect. 70E).

You also have special rights with respect to your **health information**, which are explained in this notice. We will do our best to make sure that all patients (or their parents, guardians, or legal representatives, as appropriate) receive this notice in person when they come to Dana-Farber for the first time.

This notice is being given to you because federal law gives you the right to be told ahead of time about:

- How Dana-Farber will handle your personal health information;
- Dana-Farber's legal duty to protect the confidentiality of your health information; and
- Your rights regarding your health information.

The privacy practices described here will be followed by all employees, medical staff, other health care professionals, trainees, students, or volunteers who are part of the Dana-Farber system. An up-to-date version will be available at Dana-Farber Cancer Institute. You can also obtain a copy of this notice, and a copy of our *Patient Rights and Responsibilities*, by calling the representatives listed at the end of this document. Both are available on our Web site at www.dana-farber.org/privacy.

If you have questions about this notice, or would like further information, please contact the privacy representatives listed at the end of this document.

Introduction

Dana-Farber Cancer Institute (DFCI) provides care for patients with cancer and related diseases. In addition to our main campus in Boston's Longwood Medical Area, we have established several satellite locations to provide oncology care in community settings for the convenience of our patients. We also conduct research and provide various community services, such as operating vans that go into neighborhoods to provide health services in the community, including a mobile mammography van that screens women for breast cancer, and another van that screens men for prostate cancer. The individuals who receive these screenings are also considered Dana-Farber patients, even though most of them will not have cancer.

Dana-Farber has close relationships with several other health care providers and institutions, including professionals and hospitals affiliated with Partners HealthCare System ("Partners"), Harvard Medical School, and other organizations. These relationships ensure that Dana-Farber patients have access to the finest care available. In addition, at each satellite location, we have established a cooperative arrangement with a nearby hospital to make a broader range of services available to our patients in the community. For example, Faulkner Hospital, Milford Regional Medical Center, South Shore Hospital, and Elliot Hospital in New Hampshire are each affiliated with a DFCI satellite. This means that when you are a Dana-Farber patient, a portion of your care may also take place at other hospitals, or involve their clinical staff or resources.

For Pediatric Patients

Dana-Farber and Children's Hospital Boston have an organized health care arrangement, in which both institutions work cooperatively to care for pediatric patients with cancer or related diseases. Pediatric patients are seen in the Jimmy Fund Clinic at Dana-Farber, by physicians who also have privileges at Children's Hospital Boston. Pediatric patients receive outpatient care at Dana-Farber and inpatient care at Children's Hospital Boston. Staff members at each hospital consult with each other as needed, and medical records may contain information from both hospitals.

For Adult Patients

Dana-Farber and Partners HealthCare System also have an organized health care arrangement in which oncology services for adults are coordinated through an organization known as "Dana-Farber/Partners CancerCare." In addition, Dana-Farber and Brigham and Women's Hospital (BWH), which is a subsidiary of Partners, have also formed the Dana-Farber/Brigham and Women's Cancer Center (DF/BWCC) to provide a single, combined, adult oncology service in which inpatient services are located at BWH, and most outpatient services are located at DFCI. Health information on Dana-Farber patients is available to staff at both hospitals for purposes of providing care to Dana-Farber patients.

Research

Dana-Farber conducts clinical trials and other research involving human subjects in which patients at Dana-Farber, Beth Israel Deaconess Medical Center, BWH, Children's Hospital Boston, Partners hospitals, and other hospitals may participate. Dana-Farber is also part of a consortium of Harvard hospitals and schools that coordinates basic and clinical research on cancer. The consortium is called the "Dana-Farber/Harvard Cancer Center" and has been designated by the National Cancer Institute as a Comprehensive Cancer Center.

Clinical research is very important to advancing our knowledge of cancer and other diseases, and discovering better treatments. Patients who wish to participate in clinical trials will be asked to authorize Dana-Farber to share patient information with other entities that are involved in the research. However, as discussed in the next section, Dana-Farber may always share health information with outside health care providers when sharing helps deliver care and treatment. Under federal law, an Institutional Review Board (IRB) must approve such human research. The Dana-Farber IRB approves clinical trials at Dana-Farber and acts as the designated IRB for Children's Hospital Boston for pediatric oncology, and BWH for adult oncology. In addition, the Dana-Farber IRB acts as the designated IRB for certain clinical trials conducted at Beth Israel Deaconess Medical Center, Massachusetts General Hospital, and other hospitals.

What Health Information Is Protected?

When you or your child needs health care, you give information to doctors, nurses, and other health care workers and staff. This information, along with the record of the care you receive, and information about your health care benefits under your insurance plan, is your health information. It may be kept in a paper form (such as your medical chart) and/or in an electronic form on a computer.

Your health information is “**protected health information**” when it is combined with:

- Demographic information (such as your name, address, or insurance status);
- Unique numbers that may identify you (such as your Social Security number, phone number, or driver’s license number); or
- Other types of information that may identify who you are.

Guide to this Privacy Notice

Part I of this notice will tell you how Dana-Farber uses and shares your health information.

Part II will tell you about your rights, and how to exercise them.

Part III will tell you about Dana-Farber’s duties with respect to your health information.

Part IV and **Part V** will tell you how to complain if you think your rights have been violated.

Part I. When and how we may use and disclose (share) your protected health information

Dana-Farber **uses** your health information within its system, and **shares** your health information outside its system, in order to give you excellent medical care. Dana-Farber uses and shares your health information for other reasons that can include medical research and training new health workers. Persons or companies outside Dana-Farber may receive your information to perform services on Dana-Farber’s behalf (“business associates”). Business associates must take steps to keep your health information private.

A. With your authorization or at your request

We will generally obtain your written authorization before sharing your health information with others outside the Dana-Farber system. You may also request that a copy of your records be sent to another person or entity by completing a written authorization form. You may withdraw such an authorization at any time, unless we have already relied on it. To withdraw a written authorization, please write to one of the privacy representatives listed at the end of this notice or follow the instructions on your original authorization form, if they were included.

B. Without your authorization (for treatment, payment, and operations)

Except when prohibited by state or federal laws, Dana-Farber may use and share your health information without your written authorization, for activities relating to treatment, payment, and health care operations. We do not need to ask for your specific permission to do these things, as explained below.

Treatment. Dana-Farber health-care providers will use and share your health information to provide and manage your health care and related services. For example, your primary-care doctor may refer you to an oncology specialist at DFCI. The specialist may tell you that you need to be admitted as an inpatient, for surgery. All of the doctors involved in your care may receive and use medical information about you. Dana-Farber may also share information with others involved in your care, such as home-health agencies, visiting nurses, rehabilitation hospitals, and ambulance companies, in order to coordinate your care before, during, and after you are at Dana-Farber. We may also share information with any health-care providers who may request this information to treat you in the future. This helps to make sure that everyone caring for you has the information they need.

Payment. Dana-Farber will use and share your health information to bill and collect payment for the health-care services it provides. For example, if you have health insurance, we will share your medical information

with the insurance company or government agency. They use the information to see if you are eligible for benefits, or if the services you received were medically needed.

Health care operations. Dana-Farber may use and share your health information for activities that are needed to operate our facilities and carry out our mission. (Sometimes it is necessary to give patient health information to certain outside parties, known as business associates, who perform services to support our health care operations. Business associates sign contracts with Dana-Farber that require them to take steps to keep your health information private.) Some examples of these services are:

- monitoring the quality of care and making improvements where needed;
- making sure health care providers are qualified to do their jobs;
- reviewing medical records for completeness and accuracy;
- teaching health care professionals; and
- entering and updating your health information on computers.

Dana-Farber may also use your health information to contact you at the address and telephone numbers you give us (including leaving phone messages) for reasons relating to our operations. For example, we may call or write to you with information about:

- scheduled or cancelled appointments, registration/insurance updates, billing or payment matters, pre-procedure assessment or test results;
- patient-care issues, treatment choices, and follow-up care instructions;
- other health-related benefits and services that may be of interest to you;
- DFCI fundraising programs and events in which you may be interested, using limited information (only your name, address, phone number, age and/or gender) to do so.

Purposes that do not require your written authorization

Dana-Farber may, by law, use and/or share your health information with others, for the following reasons, without your written authorization:

- For certain research activities. In most cases, we will ask you for your written authorization before using or sharing your health information for research. However, in some cases, we may use and disclose your information without your written authorization, for example, if we obtain approval from a research or privacy committee to ensure that research without your written authorization poses little risk to your privacy. In addition, we may use and disclose your health information so that we or others may plan a possible research study, identify studies in which you might be interested, or conduct research involving the health information of deceased patients.
- As required by state and federal laws and regulations.
- For public-health activities, including required reports to the state public health and child protection authorities, and to agencies such as cancer registries and the U.S. Food and Drug Administration.
- To report cases of abuse, neglect, or domestic violence. We will make every effort to get your permission before releasing this information, but in some cases we may be required or authorized to act without your permission.
- For health oversight activities, such as governmental audits, certification programs, or for compliance with government regulatory programs.
- For legal and administrative proceedings.
- For law-enforcement purposes under certain specific conditions.
- For informing coroners, medical examiners, and funeral directors about patients who have died.
- For organ, eye, or tissue donation at death.
- To avert a serious and imminent threat to the health or safety of you or another person.
- For specialized government operations.
- As authorized by and as necessary for workers' compensation or similar programs that provide benefits for work-related injuries.

- When we use or share “completely de-identified” information, in which we have removed anything that might identify you or your child. In some cases, we may share “partially de-identified” information for public health and research purposes or for health-care operations, if the person receiving the information has signed an agreement to protect the privacy of the information as required by state and federal law. “Partially de-identified information” means that it will not contain anything that would directly identify you, such as your name, street address, Social Security number, phone number, e-mail address, or license number.

C. Times when you may ask us to limit uses and disclosures

In certain situations, you can request that some or all of your health information not be used or shared. These situations, and your rights in these situations, are explained below.

Patient directories. If you are registered at a hospital, and you do not object, your name, room location, general condition, and/or religious affiliation may be listed in that hospital’s directory (at the information desk). This information, except for your religious affiliation, may be shared with members of your family, friends, and people who ask for you by name. In addition, this information and your religious affiliation may be shared with members of the clergy.

You may ask to have your name, or your child’s name, taken off the directory list, and the hospital must comply with this request. You may also ask to limit the information that is given out about you. If you are in an emergency situation and cannot make your wishes known, the hospital may put this information in the directory if we think it is in your best interest. We will not put the information in the directory if you have been admitted to the hospital before and asked that it not be shared. We will always discuss your preferences with you as soon as the emergency is over.

Sharing with family, friends, and others. If you are present and able to make health-care decisions, we will try to find out if you want us to share this information with your family members or others. If you are in an emergency situation and cannot make your wishes known, we will use our best judgment to decide whether it is in your best interest for us to share information and with whom. If we can reasonably do so while trying to respond to the emergency, we will try to find out if you want us to share this information.

Dana-Farber may use or share your health information to notify a family member or other person responsible for you of your location, general medical condition, or death. We may also use or share your health information with a public or private agency assisting in disaster relief. This is to coordinate efforts to notify someone on your behalf.

D. When special protections may apply

As discussed earlier, your written authorization is generally not needed when we use or share your information for treatment, payment, or health-care operations. However, some kinds of information are considered so sensitive that state or federal laws provide special protections for them. This means that even if the particular information relates to treatment, payment, or operations, we may need to get your written authorization, and/or your health care provider’s authorization, in order to disclose (and in some cases, to use) that information. We may also be required to obtain your written authorization before we can use or disclose these types of information to the government, to law-enforcement officers, courts, researchers, and others as we have explained. There are special protections under state or federal law for information about:

- genetic testing (as defined by state law) or the results of genetic testing;
- HIV testing or test results;
- substance abuse rehabilitation treatment programs;
- treatment for sexually transmitted diseases; and
- domestic-violence or sexual-assault counseling, confidential communications between a patient and a social worker, or confidential details of psychotherapy (from a psychiatrist, psychologist, or licensed mental health nurse clinical specialist).

Most of these require your authorization to share. But, some exceptions apply. For example, your written authorization is not required for your therapist to use or share psychotherapy notes in order for your therapist to treat you, for training programs, for legal defense in an action you bring, or for oversight of the therapist.

If you have questions about the ways that these types of information can be used or disclosed, please contact the Dana-Farber privacy representatives at the numbers provided at the end of this notice, or speak with your doctor, counselor, social worker, or therapist.

Part II. Your rights with respect to your health information, and how to exercise those rights

We want you to know you have the following rights to access and control your health information. These rights are important because they will help you make sure the health information we have about you is accurate. They may also help you control the way we use your information and share it with others, or the way we communicate with you about your health.

A. The right to ask for limits on using and sharing your health information

You have the right to ask us to limit how we use and share information about you or your child with family or friends involved in your care, or how we use and share your health information for treatment, payment, or health-care operations. You can also ask us to limit how Dana-Farber uses this information to contact you, for example, about appointments.

However, Dana-Farber is not required to agree to your request. If we do agree, we must put the restriction in writing and abide by it unless you need to be treated in an emergency. However, we cannot agree with any request that would prevent us from disclosing information when we are legally required to disclose it.

B. The right to ask us to contact you in a confidential manner

You have a right to ask that we contact you, or send your health information to you, in the way you prefer. For example, you may ask that Dana-Farber not contact you with appointment reminders by telephone, or call at your work or cell telephone number rather than home. When we ask for your preferred address and telephone numbers, you are responsible for giving us information that will allow us to reach you when necessary and to care for you. We ask that you put your special requests about being contacted in writing, and that you inform us in writing with any changes to this information. We must agree to any reasonable request and we cannot ask you to explain the reason for your request. Dana-Farber can require you to give information as to how a payment will be handled, and the address to which we can mail a bill.

C. The right to look at and get a copy of your health information

You have the right to see or request a copy of the health information that may be used to make decisions about your health care, payment for that care, and other benefits. For example, you have the right to look at and get a copy of health information Dana-Farber keeps regarding your medical treatment and bills. You must ask for this in writing. We will generally respond to these requests within 30 days, but if we need additional time, we will notify you within the 30-day time frame that we need an additional 30 days. If you ask for a copy of your records, we may charge a reasonable fee to cover the costs of complying with your request.

If your request is denied, we will explain the reasons in writing and tell you which rights you have, if any, to a review of the denial. We may give you a summary or explanation of the information you requested as long as you have agreed to this in advance and to any fees that it might involve. If you ask for information that we do not have, but we know where it is, we must tell you where to direct your request.

D. The right to change your health information

You have the right to ask us to change information in records that are used to make decisions about your health care, payment for that care, or other benefits. For example, you may request that we correct

information related to your treatment or bills if you think there is a mistake or information is missing. You must make your request in writing and give your reason for requesting the change. We have 60 days to respond to your request. If we have not been able to act on the request within this time, we will notify you that we are extending the response time by 30 days. If we do extend our response time, we will explain the delay to you in writing and give you a new date for when to expect a response.

We may deny your request if we think the information you want changed is accurate and complete as it is. We may also turn down your request if the particular items you want changed are not part of our own records, or were not created by us, or if the information you want changed is information to which you have no right of access. If we deny your request, we must give you a written explanation, and tell you what other steps are available.

If we grant the request, we will ask you to tell us who should receive the changes. You must agree to have us notify them along with any others who received the information before corrections were made and who may have relied on the incorrect information to give you treatment.

E. The right to a record of when your health information was shared without your written authorization

You have the right to get a record of the times that your health information has been shared without your written permission or authorization. You must make your request in writing. You may request this record as far back as six years. The listing you get will include the date, name, and address (if known) of the person receiving it. It will also include a brief description of the information and a brief statement of what was shared, *or* a copy of the written request for the information.

The record you may request will not include these instances when your medical information was shared:

- for the purposes of treatment, payment, or health-care operations;
- if you gave permission in writing (signed an authorization form);
- with persons involved in your care;
- with your personal representatives;
- as “de-identified” information;
- as “partially de-identified” information for purposes of research, public health, or health care operations;
- to communicate with you about your health condition; or
- for national security or intelligence purposes or to correctional institutions or law-enforcement officials who have custody of you.

We have 60 days to respond to your request. If we have not been able to act on the request within this time, we will notify you that we are extending the response time by 30 days. If we do this, we will explain the delay to you in writing and give you a new date of when to expect a response. Your first request for a record in any 12-month period is free. We may charge a reasonable fee for any other requests you make in that same 12-month period. We will notify you of the fee before we do the work. This will give you a chance to stop the request if you do not wish to pay the fee.

F. The right to ask for a paper copy of this notice

You can ask for a paper copy of this privacy notice from the contacts listed at the end of this document. You can request a paper copy even if you agreed to receive the notice by e-mail. You can also see the latest version of this notice on our Web site at www.dana-farber.org/privacy.

Part III. Our duties with respect to your health information

Dana-Farber Cancer Institute is required by law to keep your health information private. We are required to give people notice of our legal duties and privacy practices with respect to your health information.

Dana-Farber must abide by the terms of the privacy notice currently in effect. We reserve the right to change our privacy practices and the terms of this notice at any time. Dana-Farber also reserves the right to make the new notice provisions effective for all protected health information that it maintains. If it does so, the updated notice will be posted on the Dana-Farber Cancer Institute Web site and in all Dana-Farber registration areas for public viewing. You can request a copy of the current privacy notice at any time by calling the representatives listed at the end of this document, or find it on our Web site at www.dana-farber.org/privacy.

Part IV. How to complain if you believe your privacy rights have been violated

If you think that we may have violated your privacy rights, or you disagree with any action we have taken with regard to your health information, we want to know. We hope that you, your family, or your guardian will feel comfortable speaking with us. If you make a complaint, you will not be retaliated against in any way. It is the goal of Dana-Farber to respect your privacy while giving you the very best care.

You can file a complaint by contacting any of the representatives listed at the end of this privacy notice. You may also send a written complaint to the Secretary of the Department of Health and Human Services at 200 Independence Avenue SW, Washington, DC 20201, or via e-mail at HHS.Mail@hhs.gov. We will not penalize you if you file a complaint about our privacy practices.

Part V. Persons at Dana-Farber to contact for information or with a complaint

If you have any questions about this notice or any complaints, please contact a **Dana-Farber privacy representative** at **617-632-2235**.

You may also call the Dana-Farber Compliance Hotline or the Dana-Farber patient and family relations representative, at the numbers listed below.

Part VI. Effective date of this privacy notice

This notice is effective as of April 14, 2003, and has been most recently amended on Oct. 1, 2009.

Part VII. Key phone numbers

The following is a list of phone numbers you can call for more information about this privacy notice, or to make a complaint or raise concerns about your privacy rights.

- Dana-Farber patient and family relations representative: **617-632-4238**
- Dana-Farber privacy representative: **617-632-2235**
- Dana-Farber Compliance Hotline: **800-451-0659**
- Dana-Farber TDD line (for persons with speech or hearing problems): **617-632-5330**

For non-English-speaking persons:

Si necesita traducción, por favor llame al **617-632-6366**.

Для перевода на родной язык, пожалуйста, обращайтесь по телефону (617) 632-6366.

Caso você necessite esta informação, ligue para **617-632-6366**.

Για μια μετάφραση, παρακαλώ καλέστε (617) 632-6366.

للحصول على ترجمة ، يرجى الاتصال برقم الهاتف **617-632-6366**

Find more information on our Web site at www.dana-farber.com.

En Español: <http://espanol.dana-farber.org>.

Last updated on 10/1/09



Acknowledgement of Receipt of Privacy Notice

Dana-Farber Cancer Institute, along with Partners HealthCare, Brigham and Women's Hospital, and Children's Hospital Boston, is an integrated health care system. These hospitals, as well as the doctors, nurses, therapists, and other caregivers who work in these organizations, are called "providers." These providers may share patient health information for treatment, billing, and health care operations.

Federal law requires that all patients be given a copy of the privacy notice. It describes in detail how patient health information is used and shared with others.

This is our current privacy notice. Dana-Farber reserves the right to change it at any time. You may obtain another copy by contacting a patient and family relations representative or by visiting our Web site at www.danafarber.org/privacy.

Reasonable efforts will be made to protect the privacy of your health information, whether it is maintained on paper or electronically, and regardless of how it is communicated.

I have been given a copy of the Dana-Farber Cancer Institute privacy notice.

Name (print): _____ Date: _____
(Last) (First) (MI)

Medical record #: _____ Date of birth: _____

Signature: _____

When patient is a minor or unable to give consent, the signature of a parent, guardian, or other representative is required.

Signature of representative: _____ Date: _____

Print name: _____ Relationship to patient: _____

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Patient was given privacy notice, however:

Patient states that he/she has signed acknowledgment form previously. Date: _____

Patient refused or did not sign acknowledgment form. Date: _____