

We, here at the NIH Clinical Center (CC), strive to provide privacy for all our patients and to maintain the confidentiality of the sensitive personal information they share during the course of treatment. As stated in the Patients' Bill of Rights, you have the right "to expect that all communications and records pertaining to your care will be treated as confidential to the extent permitted by law." Sound policies and procedures have been put in place at the CC to support these efforts while not excessively inhibiting the traditional, open exchange of information upon which the research mission of the National Institutes of Health (NIH) rests. However, there are usual and unavoidable risks to confidentiality to be found in any health care organization and, while we will do our best, we cannot guarantee absolute and total confidentiality for any patient. Therefore, if you believe that information about you is of interest to the media, or that you are otherwise particularly vulnerable to the release of some sensitive personal information, you should discuss the matter in depth with your research team and/or the Patient Representative, who can be reached at 301-496-2626.

The collection, maintenance and use of patient information in medical records or other data storage systems at the CC is governed by laws and implementing regulations including the Privacy Act of 1974, the Freedom of Information Act and applicable provisions of the Public Health Service Act, each as amended. Under those laws and implementing regulations, employees of the NIH and the Department of Health and Human Services (HHS) may have access to any information necessary to perform their assigned duties.

In the course of its patient care activities, the CC may need to release your identifiable medical record information outside of NIH and HHS, in the situations described below:

- 1. Information may be shared with physician(s), organization(s), or an individual identified by the patient to receive ongoing medical updates.
2. Information may be shared with public carriers to inform them of patients' special requirements, such as wheelchairs.
3. Information regarding diagnostic problems, having unusual scientific value, or in order to accomplish research purposes may be shared with consultants.
4. Information may be shared with representatives of authorized accrediting agencies or organizations conducting established accreditation activities.
5. Information about certain diseases or conditions, including infectious diseases such as influenza, HIV, or suspected abuse and neglect, may be reported to governmental representatives authorized by law.
6. Information may be shared with other federal agencies, contractors or volunteers who are engaged to work directly for NIH who require access to the information in order to accomplish an NIH or HHS function.
7. Information may be released to facilitate the defense of a federal employee or the U.S. involved in a law suit.
8. Information may be shared with the National Archives and Records Administration or other authorized Federal Government agencies for mandatory records management purposes.
9. Information may be shared with tumor registries for maintenance of health statistics or use in epidemiologic studies.
10. Information may be shared with designated organ procurement organizations to facilitate donor and recipient matching.
11. Information may be shared with appropriate agencies or federal entities to assist HHS in investigating and responding to a suspected or confirmed breach.
12. In the unlikely event that a patient must be transferred emergently from the CC to an outside healthcare institution, information may be released to the receiving healthcare institution and its staff, the ambulance transport company, and the patient's insurance company.
13. If at any time, a hospital or physician who is caring for a patient needs information immediately, and if waiting to obtain permission could endanger that patient's health, information will be released. Except for the uses described above, generally medical and personal information about a patient is not given to anyone without the specific written permission of the patient.

The following offices stand ready to assist you with many aspects of information practices at the Clinical Center. Please do not hesitate to contact them if the need arises:

- Authorization for Release of Medical Information and Medical Secure Email: Health Information Management Department: (301) 496-3331
• Media Interaction and Policy: CC Communications: (301) 496-2563
• Breach of Confidentiality: Privacy Officer: (301) 496-4240
• Special Privacy Requirements: Patient Representative: (301) 496-2626

I have read this explanation of information practices at the CC, and I agree to the use of my information in this manner. I understand that I may contact any of the offices listed above if I have any questions or concerns about the use or release of my information by the CC.

Signature of Research Participant

Date

Signature of Parent/Legal Guardian

Date

Relationship to minor

Signature of Second Parent/Legal Guardian (if required)

Date

Relationship to minor

Signature of Witness

Date

Interpreter Certification (if needed):

I have interpreted to the best of my ability all items on the Notice and Acknowledgment of Privacy Practices (NIH 2753). I have also asked and translated all questions and answers asked of me by the NIH Staff and research participant to the best of my ability.

Signature of Interpreter

Date

Patient Identification

Notice and Acknowledgment of Information Practices
NIH-2753 (3-18)
P.A. 09-25-0099
File in Section 4: Authorization