

MEDICAL RECORD

Information Practices

We, here at the 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, "The patient has the right to privacy concerning the medical program. Case discussion, consultation, examination, and treatment are confidential and will be conducted discreetly. The patient has the right to expect that all communications and records pertaining to 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 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 regulation including the Privacy Act of 1974, the Freedom of Information Act and applicable provisions of the Public Health Service Act. Under those laws and implementing regulations, employees of the NIH and the Department of Health and Human Services may have access to any information necessary to perform their assigned duties. In addition, there are certain statutory exceptions and published routine uses of personally-identified information that do not require prior approval for release to individuals or organizations that are not a part of the NIH. Those are discussed at length in the Patient Handbook under Section 2: "Patients' Rights, Informed Consent, Confidentiality." In brief, they are:

- 1. Physician(s), organization(s), or an individual identified by the patient to receive ongoing medical updates.
2. The Social Work Department may share information to assist patients in the community.
3. The Travel Office may inform public carriers of patients' special requirements, such as wheelchairs.
4. Information regarding diagnostic problems or having unusual scientific value may be shared with consultants.
5. Information may be shared during audits of the operation of the CC or with accreditation organizations.
6. Congress may request information for matters within their jurisdiction or on behalf of constituent patients.
7. Certain diseases or conditions, including infectious diseases, or concerns about abuse and neglect may be reported to appropriate governmental representatives as required by law.
8. Information may be released for statistical or research analysis without personal identifiers.
9. Contractors may require access to certain information in order to provide a service. In such cases, all contractor personnel shall be subject to the requirements of the Privacy Act.
10. Information may be released to facilitate the defense of a federal employee or the U.S. involved in a law suit.
11. The Bureau of the Census or the National Archives may request records for survey, census or historical preservation.
12. Information may be released in response to a court order or for law enforcement purposes.

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. However, if at some later time, a hospital or physician who is caring for you need information immediately, and if waiting to obtain your permission could endanger your health, the information will be released immediately, and you will be notified of the release by letter. Such information may be transmitted via facsimile.

The following individuals or 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 Information: Medicolegal Section: (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
• Secure Medical Email Inquiries: Medicolegal Section: (301) 496-3331

I have read this explanation of information practices at the CC and have been given the opportunity to discuss it and ask questions. Furthermore, I understand that if I have any questions or concerns about the use of information at the CC, I may contact any of the persons or offices listed above for assistance.

Input box for authorizing records to be sent to home address or not.

Signature of Patient/Healthy Volunteer or Parent/Legal Guardian for Minor Date

Signature of Witness Date

The National Institutes of Health (NIH) Clinical Center is offering a service enabling electronic communications between patients and their health care providers and other authorized NIH staff (for example, Scheduling, Admissions, or Medical Record Department staff, etc.). By specifying an email address below and signing the form, you consent to electronic communications.

I agree to the use of secure electronic communications and specified the email address to which electronic communications can be addressed below. By signing this form I certify that I am the individual who I claim to be. I understand that the knowing and willful request for or acquisition of a medical record pertaining to an individual under false pretenses and the making of a false statement are both criminal offenses punishable by imprisonment. Specify only the email address that you frequently use and monitor:

Input field for email address with @ symbol.

Signature of Patient/Healthy Volunteer or Parent/Legal Guardian for Minor Date

Patient Identification

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