

Parents Barred From Teen Health Files

Privacy Laws for Adolescents Thwart Efforts to Expand Electronic Medical Records

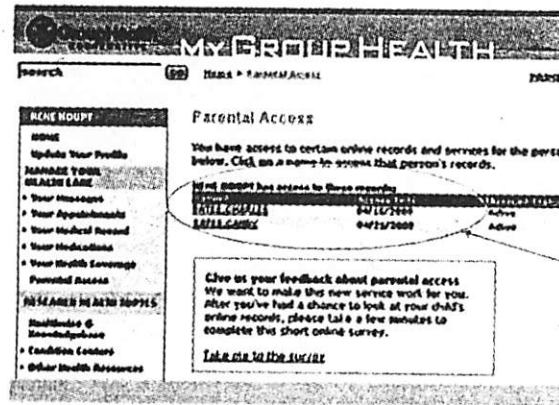
By LAURA LANDRO

USING HER HEALTH PLAN's Web site, Ursula Scott of Seattle can view the medical records of her 2- and 5-year-old daughters, check their immunization schedules, look up test results, exchange emails with a pediatrician, and make appointments for the next office visit.

But when it comes to her 16-year-old stepson, no one in the family can gain access to any aspect of his electronic medical records—including the teen himself.

In the long-running effort to balance the rights of parents and adolescents in making decisions about medical care, technology has opened up a thicket of new legal and technical issues. The result is that teens are being left out of one of the most important advances in the administration of health care today.

A growing number of health plans, hospitals and doctor's offices are making the switch to electronic medical-record systems, in response to the Bush administration's push to make online records available to all Americans within the next decade. Such systems, like the one run by Group Health Cooperative of Seattle, which covers the Scott family, offer more than just convenience. They hold the promise of faster



Access Denied: Group Health alerts parents to when they will lose access to a child's online records.

sharing of vital medical information, reduction of medical errors and more control for consumers over their care.

But with teens, these efforts risk running afoul of a complex patchwork of federal and state laws that allow adolescents to seek confidential family-planning and mental-health services without their parents' consent. Such laws make certain aspects of teens' health records off-limits to parents. However, electronic medical-records systems don't yet have a foolproof way to flag confidential material and hide it from parents—something that can more-easily be done with paper records. And as minors, teens cannot on their own enter into the security agreements required to grant access to their online records.

Until providers can figure out how to give parents access to basic health-care information for a child, without breaking confidentiality or access rules, many are leaving adolescents out of new electronic medical-records systems altogether—and revoking parental access to children's records as soon as they turn 13.

"Parents are often floored to learn that when their kid turns 13 they are still responsible for them but they can't know certain things about them," says Maureen Moran, who oversees the parental access program for Group Health.

Families still have access to paper versions of a teen's nonconfidential records, including immunizations, treatment for chronic conditions such as diabetes, and general medical care. But without access to electronic records, teens miss out on a host of benefits, including secure email messaging with their doctors.

A number of efforts are under way to find solutions. The American Academy of Pediatrics is currently revising its policy on patient rights and privacy protections for minors, to address electronic-medical-records issues. And software developers are working on more-sophisticated records systems. Group Health in Seattle hopes by next year to offer a modified version of an adolescent online health record that will allow parents to view standard nonconfidential health data, and let teens use some services such as refilling prescriptions online, says Group Health Associate Medical Director Ted Eytan.

One of the nation's largest health plans, Kaiser Permanente, is making electronic medical records available to parents. Please Turn to Page D4, Column 1

Parents Barred From Teen Files

Continued From Page D1

records available to its 8.2 million members in nine states and the District of Columbia over the next two years. The company is developing a health-care "proxy" agreement that allow adults to access medical records of adult family members for whom they are caregivers, such as a sick spouse or elderly parent, as well as minor children. But for teens, an advisory group is still trying to develop recommendations about how to proceed.

Tim McKay, a senior practice leader at Kaiser Permanente's Internet Services Group, notes that Kaiser's software has the flexibility to grant parents access to certain aspects of a teen's records, and block others. The trick is to figure out what can be disclosed. State laws, for instance, leave many decisions about whether to notify parents about protected health care up to the health-care providers.

"Who should access teen information is a difficult issue; the laws are subtle, and do not always provide clear direction," says Mr. McKay.

Parental access to teens' health information continues to be a hot-button issue 30 years after the federal government first granted wide confidentiality protection to adolescents as part of an effort to reduce teen pregnancy rates and sexually transmitted diseases. The federal Title X program requires all family-planning clinics to offer confidential services to teens. And the federal privacy law, which went into effect in 2002, extended additional protections to teens, says Abigail English, director of the Center for Adolescent Health and the Law in Chapel Hill, N.C.

Most states allow minors to consent to treatments including substance abuse, sexually transmitted diseases and men-

tal-health counseling. In Washington, for example, minors can seek treatment for chemical dependency at age 13 and seek contraception and reproductive health care at age 14, without parental consent or notification.

Group Health, which is rolling out its parental access service to its 550,000 members in Washington and Idaho, tells parents when they sign up that on their child's 13th birthday parents will lose access to his or her online records and services—because state law restricts parental access to records addressing reproductive-health and mental-health issues for youths aged 13 to 17, and it's difficult to separate those private records from the rest.

At Dallas Children's Hospital, Chief Medical Information Officer Joseph Schneider, sums up the issue: "Teens enter into this limbo land, where we can hide information from their parents, but we can't necessarily share it with them."

Efforts to come up with clear policies for adolescent health records are only likely to become more complicated. Advocates of more parental control continue to lobby to restore some parental rights. More than a dozen states have already considered repealing or modifying laws that allow minors control over reproductive health-care decisions.

Andrew Spooner, the director of general pediatrics at the University of Tennessee College of Medicine, says that eventually technology should make it possible for doctors to create records that can automatically determine by a patient's age and a state's laws what information can be accessed by a parent. In the meantime, Dr. Spooner suggests parents talk to their doctors to make clear what they want to know about and what they will trust the doctors to do without notifying them.

"The guiding principle of adolescent privacy is that certain areas of care require that an adolescent be treated more as an adult than a child," he says.

Adolescent Health

Some resources for teens and parents dealing with sensitive health-care issues:

SITE	DESCRIPTION
Alan Guttmacher Institute www.agi-usa.org	Provides fact sheets on minors' access to reproductive and sexual health care and monthly updated fact sheets on state policies.
Nemours Foundation www.kidshealth.org	Information on physical and mental health for children and teens.
Planned Parenthood's Teenwire www.teenwire.com	Features sections about birth control, pregnancy, sexual orientation, infections and diseases; information on how to find a local clinic and laws regarding teen access to birth control and other services.
Society for Adolescent Medicine www.adolescenthealth.org	Help finding an adolescent-health professional; information for teens and parents about health issues including sex, mental health and substance abuse.