MAXIMIZING THE VALUE OF HIT TO IMPROVE THE HEALTH OF CHILDREN:

A Guide for Consumer Engagement

When deployed in a manner that maximizes the value for children, health information technology (HIT) can help knit together the wide array of adults that support a child, address some of the unique health needs that children face, and tap into the technology skills and interests of today's youth. However, while HIT is often designed with the provider in mind, the transformation that it has to offer for children's health and health care will only be realized if the consumer—child or parent—is part of the equation.

This document lays out four guideposts that should govern any HIT effort to engage the consumer in their own care, with a specific focus on the unique needs of children and their parents. It also identifies core functions that can maximize the value and utility of any HIT tool that collects information from or provides information to a child and parent, such as through a personal health record (PHR), a patient portal into a health care provider's electronic health record (EHR), or a mobile monitoring device.

Connect children and youth to doctors, caregivers, and services to ensure that their care is tailored to meet their individual needs.

- *Allow for two-way, real-time communication and sharing of appropriate data among providers and other caregivers, the child and his or her family, and across data systems.* For instance, children in foster care can benefit from electronic records systems that better serve their complex health needs by exchanging health information—such as a list of their providers, services received, pharmacy records, and diagnoses—with their providers and caseworkers, keeping their other caregivers (including schools, courts, and foster parents) informed, and maintaining the record as they transition out of foster care.
- *Provide the family with convenient opportunities to keep providers and caregivers informed.* Through tools, such as pre-visit questionnaires, surveys, assessment tools, remote monitoring devices, and others, a parent can ensure that a provider receives critical information about his or her child, despite the time pressures or timing of an appointment.
- *Utilize off-site resources to help meet the unique needs of a specific child.* Telemedicine can increase consumer access to medical providers from remote locations while other basic communications tools such as automated video and voice call center systems can ensure that a family at a hospital or clinic has access to medically trained language interpreters, in real time, within seconds.
- *Offer opportunities for the family to get third party assistance that can be accessed in real time, in both human and electronic form.* For instance, online applications for health coverage can offer applicants a phone number to dial in for live assistance, a chat box to ask live questions online, and a drop-down box to help them navigate the process and submit a complete application.

- *Use information that families have already provided to help connect them to available programs.* For example, though not yet commonplace, uninsured children can enroll in subsidized health insurance through the use of online applications that use limited identifying information to retrieve relevant eligibility data held by government databases, reconcile that data, and organize it to automatically process an application or renewal determination.

Inform families with individualized tools that help them understand their health needs, assess their options, and make knowledgeable choices.

- *Present useful, clear and well-organized information at the appropriate health literacy level for the user and in multiple languages.* For instance, migrant agricultural laborers (through the MiVIA program) can access an electronic personal health record for themselves and their children that includes insurance details, a photo for identification, a library of targeted resources in Spanish and English, and other information that can be hard to retain in such mobile lives.
- *Help parents follow their child's care, tests, and medicines, and support them in making relevant decisions.* Home-based decision support tools can provide tailored, understandable self-management information that is responsive to an individual's health or disease experience. For example, Web-based asthma management sites allow children and parents to gauge the severity of an episode and determine appropriate medication strategies or when to seek medical help.
- *Provide information that engages and speaks specifically to individuals of different ages*. For example, social networking sites for children with specific conditions (such as the Starlight program for children with cystic fibrosis) allow families to communicate about medication, treatment, and other common experiences, giving them a uniquely useful body of information that they can evaluate and use as they see fit in addition to connecting them with a supportive community.
- *Automate the provision of notices, reminders, and alerts that are individual to the patient.* The federal Text4Baby program, for example, provides automated, periodic text alerts and reminders about prenatal and newborn care that is relevant to thousands of specific individuals as determined by their due date or birth date.

Empower children, supported by their parents, to actively and effectively participate in their own health care.

- *Open up new communication channels that will improve access to providers and services.* These new channels (whether through e-mail, texting, or online) can allow parents to receive reminders, schedule appointments, submit forms, make payments, and discuss their child's care at times and in a manner that works best for them. Tools like mobile monitoring devices can also help the child and parent consumer remotely communicate important health information, such as glucose levels, to providers.
- *Enable a parent to view, print, save, and export a child's data in a format that can be used, reused, and tracked.* For example, the U.S. Department of Health and Human Services is working on making a "Blue Button" available to veterans and eventually others that allows consumers to download their health information for their own use from secure Web sites operated by medical practices, hospitals, pharmacies, insurers, and laboratory services.

- *Involve families in overseeing the quality of their records.* For instance, a parent can review and manage a child's health record through a patient portal that allows them to identify missing information that could impact the child's care, rectify any errors, and use the data to populate consistent information across family records and applications.

Protect children and youth through appropriate privacy and security policies.

- *Educate families on applicable privacy policies and options and enable them to have meaningful control of their own information.* For instance, HIT can help consumers embed privacy specifications into the data in their records in order to address what data are available, to whom, and for what purpose. For example, a parent can authorize periodic transmission of immunization records to school authorities and immunization registries while withholding other clinical records.
- *Maintain an immutable audit trail that includes read, write, edit, and download tracking*. Such systems help families monitor the use of their data and can build trust, when combined with vigorous enforcement of privacy rules.
- *Prevent the unauthorized disclosure and use of health data.* To achieve such protection, strong authentication policies as well as privacy and security requirements that are at least as strong as HIPAA can be applied.

Technology has transformed the way we learn, communicate, and live. Its application in the world of health care is changing the way we receive health care information, interact with our doctors, and manage our care. Ultimately, the application of HIT holds the promise of making us a healthier nation by expanding access; promoting coordinated, preventive, and patient-centered care; and simplifying the way people enroll into and renew their coverage. Achieving that outcome requires that HIT is designed to engage children and their parents—connecting, informing, empowering, and protecting them through better access to and use of electronic health information.

For More Information

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HOW HIT CAN ENGAGE CONSUMERS:

The Experience of a Youth in Foster Care

Children and youth in foster care often have complex health needs and receive care from several providers and entities as they move through the child welfare system. The following hypothetical scenario illustrates how various HIT tools can connect, inform, empower, and protect this population in a manner that can be useful for other children and families as well.

Matthew, a fourteen-year-old boy, entered the foster care system and lived in a group home. During this time, he received health care through the state's Medicaid program and was able to see a doctor for the first time in a long while. At his doctor visit, he received a complete physical examination and various health screenings. At the time, a public health nurse also helped Matthew to create a personal health record (PHR) and showed him how to import relevant information from the electronic health record (EHR) maintained by his doctor. To keep his caseworker informed, Matthew was also able to ask the nurse to forward appropriate information from his EHR to her.

After living in a group home for a few months, Matthew went to live with his Aunt Susan, who he had only met a few times. Upon signing Matthew up at his new school, his aunt was informed that she must provide proof that Matthew received the Tdap vaccine. Matthew tells Susan that he thinks he got the shot. Together, they log into Matthew's PHR from Susan's laptop and are able to see that he received the Tdap booster shot and to print out the official record of his immunizations for his school, saving them the cost and negative side effects of having a duplicate immunization.

To ensure that Matthew has received all other necessary shots for his age, Susan also uses a decision support tool—an online survey that provides recommendations for vaccinations based on age—that is available through his PHR. Susan learns that she should ask Matthew's doctor to check the State Immunization Registry to determine whether Matthew has received vaccinations for Hepatitis A and B and Meningitis.

When Matthew is next due for a check-up, Susan is able to request an appointment through the doctor's Web site. She also is able to include her question about vaccinations in the comment box as well as alert the doctor to some concerns she has about his eating habits. Susan receives an e-mail confirmation with an appointment date and time and confirmation that Matthew needs those vaccinations. At the appointment, Matthew's doctor talks to him about healthy eating and gives him the vaccinations.

After the appointment, Matthew is able to update his PHR with this new immunization and health information. He and Susan then create a subrecord of the PHR that Susan can access with her own user name and password. They select settings that will allow Susan to view most of Matthew's information while he is in her care, but will ensure privacy now and as he gets older.