



PRIVACY RESOURCES THAT CAN HELP INFORM THE DEVELOPMENT OF ELECTRONIC INFORMATION SHARING AND RECORDS FOR CHILDREN AND YOUTH IN FOSTER CARE

As detailed in [Improving Care Coordination for California's Children and Youth in Foster Care Using Integrated Personal Health Records: A Strategic Plan of Action](#), given how beneficial information sharing can be for children and youth in foster care, privacy challenges should not stall efforts that can benefit so many. Rather, a careful approach should be taken to selecting data and deciding who can see it, attempt to get appropriate authorizations up front, and leverage technology to provide data segmentation and privacy preference management capabilities. As necessary, it may be important to clarify the rules surrounding information sharing to promote the best interests of these children and youth. Transparency and user control can help promote trust, which will then promote the use of such tools to the fullest effect. The following resources can help tackle this challenge.

- **The Office of the National Coordinator** has developed a PHR Model Privacy Notice to promote trust in a PHR environment. See <http://www.healthit.gov/policy-researchers-implementers/personal-health-record-phr-model-privacy-notice>.
- **The President's Council of Advisors on Science and Technology Data Segmentation Initiative** has developed prototypes and deployed pilots to advance this capability. See <http://wiki.siframework.org/Data+Segmentation+for+Privacy+Homepage>.
- **The Bureau of Justice Assistance and the National Center for State Courts** have developed a number of materials and training modules that comprise a relevant "Privacy Policy Primer." See <http://www.TechnicalPrivacyTraining.org/>.
- **The Child Welfare League of America and the Juvenile Law Center**, working with the **Robert F. Kennedy Children's Action Corps**, have issued a number of useful materials, including an Information Sharing Toolkit. In addition, they conduct an annual information sharing certification program. See <http://www.rfknrcij.org/resources/>.
- **The National Resource Center for Child Welfare Data & Technology** has developed "The Privacy Policy Development Tool" to help stakeholders develop and manage an information-sharing enterprise's privacy policies. The tool provides the technical requirements for authentication and access controls in a formation that can easily be implemented. See <http://www.nrcwdt.org/data-sharing/>.
- **The California Administrative Office of the Courts (AOC)** has published a series of briefings entitled "Sharing Information About Children in Foster Care," which lay out the guiding law as relevant to different types of data (health, mental health, etc.) in California. See the section entitled "Juvenile Dependency" at <http://www.courts.ca.gov/cfcc-publications.htm>.
- **California's Office of Health Information Integrity (CalOHII)** has developed a set of tools to support health information exchange, including a number of HIPAA-focused privacy tools for patients and providers. See: <http://www.ohii.ca.gov/calohi/content.aspx?id=11>.
- **Orange County, California**, has developed an ID solution (OCID) to provide access and use management capability for county-based agencies regarding juvenile justice and other data. See <http://www.technicalprivacytraining.org/resources/videos.html>.

For more information, contact Beth Morrow, Director of Health IT Initiatives, at bmorrow@childrenspartnership.org or visit our website at <http://www.childrenspartnership.org>. The Children's Partnership is a national, nonprofit organization working to ensure that all children, especially those at risk of being left behind, have the resources and opportunities they need to grow up healthy and lead productive lives.