

## Registry Information

A survey was emailed to all states listed on the [National POLST Registry Map](#) (2020) as actively working on, piloting or has a registry. The tables below address the common questions received by POLST Programs.

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## Registry Ownership & Costs

State (Start Date)	Owner, Administrator Information	Where Registry is Housed	Implementation Costs	Annual Costs	Current Staffing
<b>CA</b> 2017 (pilot of multiple regional registries) Collaboration among registries began following passage of legislation (SB-19 2015)	Various, including Care Directives, Health-e-MedRecord, San Diego Health Connect, and Vynca	varies	Varies	Varies	varies
<b>CO (in development)</b>	Colorado Dept. of Public Health & Environment	TBD	A Statewide System for Advance Health Care Directives was signed into law on May 16, 2019.  An appropriation of \$993,147 for the 2019-20 state fiscal year was earmarked for the health department. Breakdown as follows: \$32,100 for personnel services (assumed additional 0.5 FTE), \$211,047 for operating expenses and \$750,000 for purchase of information technology services.	unknown	Developing
<b>DE (2018)</b>	Delaware Health Information Network				
<b>LA (2010)</b>	Louisiana Health Care Quality Forum	Amazon's AWS Cloud	\$400 - \$450K Includes initial spend to get registry implemented, staffing, and development of education/training materials	\$100-125K (includes subscription fees & staffing)	Approximately: 1 FTE: HIT staff 1 FTE training & education
<b>ID (2007)</b>	Transitioning from ID Secretary of State's office to ID Dept. of Health & Welfare	n/a	Unknown. Cost of implementation & maintenance was absorbed by Sec'y of State's office. No funds earmarked. Formal evaluation of costs being done during transition.	unknown	None. Workload incorporated into existing roles.
<b>MA (2020)</b>	In development by state officials				

<b>NV (unknown)</b>	Secretary of State		Unknown (line item in NV state budget)	unknown	unknown
<b>NY (2011)</b>	Excellus Blue Shield, a nonprofit insurer				
<b>OR (2009)</b>	Oregon Health Authority; Oregon Health & Science University (OHSU) Department of Emergency Medicine	OHSU servers	\$250K (2009)	\$370 -\$500K (year 10)	6.5 FTE
<b>PA (2019)</b>	PA Department of Human Services, Office of Medical Assistance, PA eHealth Program	IBM Watson Health (System Vendor)	\$187,000	20% of initial costs	1.5 FTE: .5 FTE: Project Manager (1) .5 FTE: Human Services Program Specialists (2)
<b>SC (2020)</b>	SC Coalition for the Care of the Seriously Ill (CSI)	My Life Choices	\$600K for staff (admin, planning, legislation, technology via Vynca)	\$45K	.5 FTE for program manager
<b>UT (2020)</b>	Utah Health Information Network (UHIN)	eHIE		Total cost for ongoing maintenance is still being determined. UHIN has incorporated this scope into existing registry work like immunization and death certificates. A CMS 90/10 grant was also obtained for \$837,155 to help support the registry build and education to post-acute facilities for completion of POLST for their residents and upload to the registry.	No new hires; using existing UHIN employees & volunteers.
<b>WV (2010)</b>	West Virginia Center for End-of-Life Care	Local Data Solutions' secure hosting of a SharePoint site with Microsoft Access integration; in the process to be hosted through Local Data Solutions' secure hosting with Azure	\$244,140: \$60,000 startup cost for custom application; \$150,000 in salaries/wages/fringes (2 full time employees and 1 student worker) for minimum effective number of employees; \$11,640 monthly secure server hosting charges for the Registry; \$2,500 in secure faxing services for forms submitted to the Registry; \$15,000 in postage for registry related letter mass mailings; \$5,000 in supply printing for mass mailings	\$184,140: \$150,000 in salaries/wages/fringes (2 full time employees and 1 student worker) for minimum effective number of employees; \$11,640 monthly secure server hosting charges for the Registry; \$2,500 in secure faxing services for forms submitted to the Registry; \$15,000 in postage for registry related letter mass mailings; \$5,000 in supply printing for mass mailings	1 FTE for program manager; 1 FTE for database manager .5 FTE for volunteers

## Registry Connectivity and Access

State	Documentation Completion	Mandated Submission to Registry	Method of Access to Registry	HIE Integration	Bidirectional EHR Integration	Electronic EMS access	EMS Access via Call Center
CA	Paper form upload Electronic form completion Electronic fax submission (available for some organizations)	No	EHR and ePCR with optional web-based portal for upload.	Yes, where HIE is present.	Yes	Yes	Back up call center for EMS for one pilot site (discontinued in 2019)
	<i>Other: Can alert providers of existence of POLST upon transition of care</i>						
CO	TBD, likely paper form and requirement for Electronic Affidavit when provider signatures are required (MOST; CPR directive)		TBD	TBD	TBD	TBD	TBD
DE	Paper form Electronic form completion	No	Web-based portal	No	No	Yes	No
LA	Paper form upload Electric form completion	No	EHR and web-based portal	Yes	Yes	No	No
	<i>Other: Contains documentation supporting POLST Form (e.g., conversation notes, medical condition)</i>						
ID	Paper form upload		Web-based portal or by phone through Sec'y of State's office (M-F 9-5).	No	No	Yes	No
MA	Paper form upload Electronic form completion		Web-based portal	Yes	Yes	Yes	No
NV	Paper form upload Fax		Web-based portal				
<i>Other: Entities must sign up to have access. This repository stores directives, POLST and guardianship information.</i>							
NY	Electronic		Web-based portal	Yes	Yes	Yes	No
OR	Paper form upload Mailed Electronic form completion Electronic fax	Yes	Web-based portal and call center-based system. Access also available via Emergency Dept Info Exchange (EDIE)	No (previously yes, but ended in 2018)	Yes	No	Yes
PA	Electronic		EHR and web-based portal	Yes	Yes	No	No
SC	Paper form upload Electronic form completion	No	Web-based portal	No	No	Yes	Yes
	<i>Other: Has ability to contain documentation supporting POLST Form (e.g., conversation notes, medical condition)</i>						
UT	Paper form upload Electronic form completion Electronic fax Mailed in forms	No	EHR ePCR Web-based portal	Yes	Yes		
	<i>Other: Medical condition noted on the POLST form but no conversation notes uploaded. Working on capacity to contain supporting documentation.</i>						
WV	Paper form upload Electronic fax submission Mailed in forms	No	EHR, Web-based portal, call center, faxed requests, mailed requests, and secure, encrypted email requests	Yes, with the WV Health Information Network	No	Yes	No
	<i>Other: EMS access; 24/7 provider access; contains advance directives and medical orders; can contain documentation of non-health care advance directives; can contain registry specific internal documents and notes; contains internal record of changes to the patient record and patient's files; contains internal record of history of patient files being accessed; based on a multi-level quality improvement system; contains death records reported to the state; can be accessible to treating health care providers not within WV</i>						

## Additional Registry Information

This information was also requested from respondents, here are the data reported from the 3 states that responded:

Louisiana; South Carolina	West Virginia
<p><b>Key technology backbone elements or infrastructure to support the registry. (i.e. SQL servers, etc.):</b> The technology infrastructure is managed by Vynca and is deployed on Amazon Webservices (AWS). Key infrastructure components include:</p> <ul style="list-style-type: none"> <li>• Amazon Virtual Private Cloud (VPC)</li> <li>• Amazon S3 - document storage</li> <li>• Amazon RDS - relational database for application and analytics</li> <li>• Docker/Kubernetes - auto-scaling application containerization</li> <li>• Amazon Cloudfront - content delivery network (CDN)</li> <li>• Mirth Connect - FHIR/HL7 data exchange and ingestion</li> </ul> <p><b>Is there a high availability plan in place?</b> Yes. virtualization, auto-scaling and containerization to deploy our solution across multiple availability zones for redundancy, recovery, and burst capacity.</p> <p><b>Is there a disaster recovery plan in place?</b> Yes. Formal Business Continuity and Disaster Recovery (DR) plan that includes:</p> <ul style="list-style-type: none"> <li>• Remote access capabilities, data backup and recovery, and alternate facilities, with a defined Maximum Tolerable Downtime (MTD), Recovery Point Objective (RPO), and Recovery Time Objective (RTO)</li> <li>• We perform annual tabletop walkthrough and exercise of the DR plan; plus ongoing use of remote access and response to disaster scenarios</li> </ul> <p><b>Key network security requirements used to ensure this registry is securely hosted and maintained:</b></p> <ul style="list-style-type: none"> <li>• A written privacy and security program based on ISO/IEC 27001:2013 and NIST-800-53 frameworks.</li> <li>• Security-by-design practices, need-to-know/minimum necessary standards, and has implemented role-based access controls (RBAC), and security awareness training.</li> <li>• Multiple technical security controls including: Virtual Private Cloud (VPC), Security Group firewalls with stateful packet inspection, Internet gateway, load-balancers, network segmentation, centralized logging, AlertLogic IPS/IDS, AWS Shield DDoS protection.</li> <li>• Security vulnerability management and patching program, security incident response, software development lifecycle (SDLC), and change management processes.</li> </ul>	<p><b>Key technology backbone elements or infrastructure to support the registry. (i.e. SQL servers, etc.):</b> Data hosting with Local Data Solutions, SQL, Azure, Microsoft Access, SharePoint</p> <p><b>Is there a high availability plan in place?</b> Yes; we are currently in process with Local Data Solutions to build a custom application to improve the longevity and functionality of our Registry. Also, our Registry’s data is available through the WV Health Information Network (WVHIN) to improve the availability of the data to treating health professionals. Once Local Data Solutions finishes the upgrade, patients will be able to access their file in the Registry to check for latest document being stored.</p> <p><b>Is there a disaster recovery plan in place?</b></p> <ol style="list-style-type: none"> <li>1. Internally at the WVCEOLC/WV e-Directive Registry, no data is stored on our local drives. All the data is hosted off-site through LDS. In addition, WVU has numerous encryptions and plans in case a security breach happens at the University level; although, this wouldn’t impact us since all the data is stored off-site.</li> <li>2. LDS’ disaster recovery plan includes data protection services to prevent the loss of SharePoint Online data, routine data backups every 12 hours with the backup retaining for 14 days, 2-factor deletion system with a 90-day grace period to prevent accidental deletion of important patient records, 14-day grace period after 2-factor deletion of data to allow us the opportunity to restore “permanently” deleted information, ability to restore the entire SharePoint library (documents, files, history, etc) to a previous version in the event of disasters (unwanted deletions, overwritten data, corrupted files, malware infection) which will undo all of the actions that occurred on the data in the 30-day period prior to the recovery, resiliency and recoverability options built into SharePoint Online through Microsoft, and a complete backup internal copy located on secure LDS servers in the Azure cloud storage.</li> <li>3. WVHIN is part of CRISP (the Chesapeake Regional Information System for our Patients). As the governing body of WVHIN, all of CRISP’s protective measures are applied to WVHIN. CRISP has the HITRUST Certification and HIE certification, follows the guidelines of the Maryland Department of Health (CRISP’s origin is in Maryland), conducts an annual review and audit, performs a bubble plan every quarter, and runs an annual disaster plan test on all the data shared with and available through CRISP/WVHIN.</li> </ol> <p><b>Key network security requirements used to ensure this registry is securely hosted and maintained:</b> Password protected database; 2-factor daily security authorization to the network (SharePoint); full data encryption through LDS; multi-factor authentication for all users; content stored as encrypted blobs in the blob store; SQL server database for the content database; encrypted keys to access each encrypted file; securely stored encrypted keys located separately in the content database; no hint of the decryption process of the keys stored in the content database; physical separation between the blob store, the content database, the key store, and the map; security measures to prevent access to the Registry’s data without gaining access to all keys, blob store files, content database, and the map</p>