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Practice Summary & Implementation Guidance

# The R.U.S.H Initiative
# [Rare & Under-Served Health]

The R.U.S.H Initiative from Beyond Lucid Technologies combines an interoperable pediatric special health needs registry and local clinical partnerships so responders can know a young person's needs even before arriving at the scene of an emergency.

Cutting-Edge → Emerging → Promising → Best

**Location**

National

**Topic Area**

Emergency Preparedness, Care Coordination

**Setting**

Community

**Population Focus**

CYSHCN, Medical & Public Health Professionals

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## PRACTICE DESCRIPTION

Today, limited awareness of patients' special health needs (SHNs) leads to avoidable risks during emergencies. If Responders knew about a young patient's visible or invisible SHNs—including all of those that have been identified by the Centers for Disease Control & Prevention, including physical, developmental, behavioral, or emotional challenges, disabilities and long-standing medical conditions, as well as associated comfort items, safe words, or even a heads-up that the patient needs mobility, communication, breathing, or other assistance—Responders would better equipped to efficiently engage, with less time spent focused on collecting clinical background during stressful moments. Leaders from the fire services, emergency medical services (EMS), public safety, hospitals and other care providers, educators, and parents have expressed particular desire for pre-arrival details about patients who need special assistance during natural or man-made disasters that require school or workplace evacuation.

During an emergency that involves one or more SHN patients, the healthcare ecosystem as a whole will benefit from Responders—i.e., firefighters, medics, and public safety officers—having rapid access to relevant details, and the ability to share them with receiving hospitals via existing conduits like public health information exchanges.

The R.U.S.H. Initiative is predicated on an intimate and longtime awareness of Responders' workflows: it combines an interoperable registry technology with local clinical collaborations to empower the range of public health and public safety stakeholders who care for SHN patients. While the R.U.S.H. Initiative is designed to address the needs of Children & Youth with Special Health Needs (CYSHN), it has no "age out" because the miracle of medicine lets children with SHN grow up to become adults with special health needs who benefit from prearrival readiness. The following is from the AAP Policy Statement titled "Access to Critical Health Information for Children During Emergencies: Emergency Information Forms and Beyond," published in 2023 by the AAP's journal Pediatrics:

> *"In disasters, access to a medical home may likely be absent for many children, and children may be separated from family members while they need medical care. Such a summary would also be valuable when language, health literacy, or other communication barriers impede obtaining information even from family members who are present…*
>
> *During emergency care (both in the out-of-hospital setting and in the emergency department) and during disasters, children receive care from a wide variety of health care professionals. These professionals include, but are not limited to, physicians (emergency physicians, pediatricians, family physicians, pediatric specialists, and other specialists), nurses, APRNs and PAs, emergency medical technicians, paramedics, mental and behavioral health specialists, and social workers. Delivering care during emergencies and disasters can truly be thought of as a "team sport," and an organized summary of important information, as advocated for in this policy statement, will help all members of those teams as well as the patients and their caregivers the team is serving.*
>
> *"However, in light of significant advances in the adoption of EHRs and improved interoperability, it is time to readdress the components necessary to provide emergency and urgent care and how these are recorded and delivered. Reports from families, emergency physicians, and other nonphysician clinicians, including out-of-hospital professionals, as well as findings from limited research, have shown the EIF to be useful for*

*CYSHCN and others who, because of age, language, or other barriers, may not be able to communicate effectively with first responders or emergency medical services or with members of the ED care team. Its utility is limited, however, by a lack of adoption and natural workflows and incentives for physicians and other nonphysician clinicians to provide and maintain the information reliably.*

The R.U.S.H. Initiative was inspired by related work—the HERO Kids Registry (Health Emergency Ready Oregon)—which was deployed by the Oregon Center for Children & Youth with Special Health Needs (OCCYSHN), Oregon's Title V agency, and is powered by the same back-end architecture (i.e., the MEDIVIEW S.H.I.N.E. Registry, which is further elaborated in the next section). OCCYSHN identified a specific challenge that is also faced by excellent clinical navigation or premise alert programs like the SSM Cardinal Glennon STARS program in Missouri and Florida; Project Austin in Nebraska; CHIRP in Utah; the Handle with Care Registry in New York; Smart911 in Washington, D.C.; and the Special Needs Awareness Program (SNAP) programs deployed by police departments in California, Oklahoma and elsewhere. The difference between the R.U.S.H. Initiative and these regional programs is that R.U.S.H. is a "network of networks"— the regional programs are community specific, which can prove challenging if and when a patient has a medical emergency outside of the location in which he or she normally lives. Historically, SHN programs that are known for outstanding clinical quality and careful navigation have been limited in their scalability and ability to engage Fire, EMS, and Public Safety teams because **(1)** they are tied to a specific geography, agency or healthcare system, and **(2)** the workflows and data standards used by Responders differ from those of hospitals and health systems. By contrast, the R.U.S.H. Initiative is more like an umbrella that can encompass and interoperate collaboratively across local or regional programs, enabling critical details to move securely—in a legally compliant and privacy protected manner—across the healthcare ecosystem so that Responders and Clinicians can access critical information timely, no matter where the emergency occurred.

As a result, when patients move around—either permanently or when traveling for vacation, for school or work, etc.—vital clinical details (including, but not limited to, POLST and emergency information forms (EIFs)) often fail to travel with them. Travel can therefore require extensive and complex planning by families, teachers, school nurses, and administrators; some have to go so far as to take envelopes with medical papers on the road. This burden even impacts community centers that specialize in engaging young people with complex care needs, like Camp Burnt Gin, which is funded by South Carolina's Division of Children & Youth with Special Health Care Needs. According to camp director Marie Aimone, in 2024 patients' health records are still stored on paper and physically handed to Mobile Medical professionals when an ambulance gets called in to assist. But the time from ambulance call to hospital arrival may take an hour, and the crew has little to no information about the patient's special health needs before they reach the camp.

## CORE COMPONENTS & PRACTICE ACTIVITES

The R.U.S.H. Initiative is powered by Beyond Lucid Technologies' MEDIVIEW S.H.I.N.E. Registry. S.H.I.N.E. stands for **S**pecial **H**ealth **I**nformation **N**eeds for **E**mergencies, and this rapidly deployable, infinitely scalable technical backbone provides a structured approach to capturing and conveying data across an ecosystem of care. "Infinitely scalable" means that BLT's MEDIVIEW S.H.I.N.E. Registry can serve all U.S. states and territories, and even be localized in terms of both language and data storage requirements to cross international lines as well. In fact, the Beyond Lucid Technologies team has a strong mission orientation and desire to deploy the R.U.SH. Initiative in service of refugee communities crossing country lines to seek safety, who need to take medical details with them.

The data captured and conveyed using the MEDIVIEW S.H.I.N.E. Registry align with standards such as the National EMS Information System (NEMSIS), which is mandatory to document care in an ambulance, as well as with federal standards for hospital-based data. This alignment not only helps to structure data in a manner that is familiar to clinicians and therefore easier to act upon quickly, it also reduces clinicians' documentation burden (a major source of stress for them) by enabling certain data to be pre-filled from the registry, therefore easing adoption.

The MEDIVIEW S.H.I.N.E. Registry shares data through existing channels that connect to electronic health record (EHR) systems such as Epic and Oracle Health. For example, several states—including Oregon, where the H.E.R.O. Kids Registry was the first statewide registry of children and youth with special health needs—use an interfacility communication network called the Emergency Department Information Exchange (EDIE) to send data between hospitals when a patient is transferred or transported, avoiding redundancy and increasing readiness. Data received via the EDIE is viewable inside a hospital's EHR. The MEDIVIEW S.H.I.N.E. Registry deposits data into the EDIE stream, giving receiving hospitals a heads-up about CYSHN patients who are being transported by ambulance.

Core to the structure of the R.U.S.H. Initiative is the reliance on community-centric models that even adopt a local name to highlight that the key stakeholders are trusted local experts comprised of firefighters, medics of all certification levels, public safety officers, physicians, nurses, school nurses, parents and guardians, and of course, patients themselves. The goal is simple: to facilitate informed, ready, and safe emergency response for patients and care providers alike, no matter what a child or young person's special health needs, whether the disaster is natural or man-made. The R.U.S.H. Initiative therefore places no limits on the clinical conditions that fall within its purview, and specific attention has been paid to overcoming demographic barriers to care, including the ability to present the R.U.S.H. Initiative's technical interfaces and introductory / training materials in multiple languages.

As noted above, the R.U.S.H. Initiative has no "age out": Previously called the R.U.S.H. Initiative for Children, the program was expanded in recognition that a goal of the medical community is to enable young people with SHNs to maximize their lives  Thanks to the miracle of medicine, some conditions—e.g., Type 1 diabetes—have become chronic, such that facilities from Cincinnati Children's Hospital Medical Center to Lucile Packard Children's Hospital at Stanford University have described caring for geriatric patients that have lived with pediatric health needs since childhood.  The following is a non-exhaustive list of conditions in focus of the R.U.S.H. Initiative: Cancer, epilepsy, autism, cystic fibrosis, sickle cell disease, diabetes, asthma, muscular dystrophy, multiple sclerosis, and rare diseases affecting metabolism, connective tissues, heart, blood, lungs, endocrine, neurocognition, mental and behavioral health.  This breadth is what we mean when we call the R.U.S.H. Initiative a "Big Tent" project: the clinical collaborations and technology are meant to serve to all with serious healthcare needs who stand to benefit from sharing critical data with Responders before they arrive on-scene and/or transport the patient to a hospital.

## Core Components & Practice Activities

| Core Component | Activities | Operational Details |
|---|---|---|
| Data Capture & Documentation | Patients and families can opt-in to provide CURATED data regarding the special health needs of children and youth, into a simple and secure web portal that can be translated (using browser-embedded A.I.) into dozens of languages for ease of understanding and completion. | The R.U.S.H. Initiative uses a data portal – powered by the MEDIVIEW S.H.I.N.E. Registry ("Special Health Information Needs for Emergencies") – that simply and efficiently collects data that are targeted to the information needs of emergency responders in the field, as well as the receiving emergency departments. It is not designed to be a replacement for an electronic health record, but more akin to a complex set of triage notes that provide very specific and actionable awareness. |
| Data Aggregation and Analytics | Securely store and analyze data entered in the registry and provide notification to local emergency medical services so that they can make contact with patients and their families. Among other resources, past EMS transport records provide a view of who has needed assistance in the past—and therefore who may benefit from proactive outreach to avoid a healthcare crisis and/or to ensure readiness to respond during a crisis. | The ability to securely store and analyze registry data enables community stakeholders to confidentially connect with patients and families (e.g., via emergency responders, social workers, etc.) who may not know that individuals with special health needs are living in the community. In many cases, those patients and their families are fearful to reach out (e.g., due to immigration status) or they may not realize the resources that are available to them (e.g., that Fire/EMS services can offer proactive care to avoid an emergency, rather than reacting to one); or that they can flag an address as high-risk using a "Premise Alert" that ensures readiness to deliver specific care to a patient with special health needs, electricity dependent medical devices, or other sensitivities. |
| Data Transmission During Emergencies | The combination of always-on, secure, interoperable technology and local clinical partnerships ensures that emergency responders know who, what, where, why, and how to engage high-risk patients across their community—or even across the country—with minimal need to interview parents, school nurses, | Data captured by the system can be accessed using a variety of means during an emergency, including electronically (i.e., within an ambulance-based electronic patient care record and/or a no-cost, phone-based app); or via a health information exchange or emergency department information exchange (in accordance with local regulations); or the data can be printed |

bystanders, etc., during the stressful moments of a healthcare emergency (or, for example, a mass casualty incident occurring at a school, during which young people with special health needs face even higher risks than others due to physical, cognitive, or other limitations).

using an Emergency Information Form (EIF) structure. Any / all of the above have been inspired by a call for more actionable real-time information by the American Academy of Pediatrics and others clinical stakeholders; as well as local / regional programs such as the STARS Registry at SSM Cardinal Glennon Hospital in St. Louis and Galisano Children's Hospital in Fort Myers, Florida. Both of these programs (and others elsewhere in the U.S.) provide excellent clinical navigation but are hamstrung by the reach needed to ensure that information about patients' special health needs are accessible anywhere in the U.S. (or even beyond), to enable safe travel. The R.U.S.H. Initiative uses an approach that is infinitely geographically scalable.

## HEALTH EQUITY

The R.U.S.H. Initiative has no limit on the clinical conditions that fall within its purview: specific attention has been paid to overcome all demographic barriers. Any child, of any race, religion, socioeconomic status, national origin, citizenship status, immigration status, housing status, sex, gender, language or any other demographic criterion, can be (or become) a patient with complex and underserved health needs. BLT's MEDIVIEW S.H.I.N.E. Registry, which powers the R.U.S.H. Initiative from a data perspective, can be presented in any language that is supported by a modern web browser such as Google Chrome or Microsoft Edge. It can exclude address collection to stanch concerns about disclosure of location and/or underhoused status. Responders and Clinicians who access the application during emergencies do so in a manner that complies with HIPAA, FERPA, 42 CFR Part 2, and local laws.

## EVIDENCE OF EFFECTIVENESS

The Oregon Center for Children & Youth with Special Needs was the first in the United States to deploy a statewide registry of medical complex children and youth people, and to ensure that data about those patients is available to Responders across the state, from urban to super-rural environments. As a technology partner, OCCYSHN chose Beyond Lucid Technologies, whose MEDIVIEW S.H.I.N.E. Registry architecture had previously proven its ability to interoperate with statewide critical health data systems (including for end-of-life medical orders, known as POLST forms), as well as hospitals, individual clinicians who provide guidance to families, and the range of Responders.

In 2023, the U.S. Administration for Strategic Preparedness and Response highlighted Oregon's groundbreaking achievement in service of young people with complex care needs and all who care for them: "…the Health Emergency Ready Oregon (HERO) Kids Registry, which is a voluntary, no-cost registry that lets families record critical details about their child's health so first responders and hospital emergency departments can quickly and easily access that information in an emergency." The same technology backbone powers the R.U.S.H. Initiative.

The name that the state of Oregon chose for its programs highlighted a truth about engaging communities of need, including patients with complex illnesses and their families: Yes they need to be able to scale and follow the patient, so that they are "free to move about the country" (to borrow the words of Southwest Airlines) and maximize their lives. But still, there is a special intimacy involved in the care of such patients, so programs geared toward CYSHNs benefit from a "hyperlocal" approach. Therefore, the R.U.SH. Initiative invites communities to brand their program—using names, fonts, colors, logos, etc.—so as to resonate with the community while keeping the captured and shared data consistent. For instance, in Virginia, where the R.U.S.H. Initiative is deployed on a statewide contract using the brand name "Kids of VALR Program," the acronym stands for "Virginia Life Registry."

**The following are key highlights from the HERO Kids Registry deployment across Oregon:**

- Between September 2022 and December 2023, 254 children and young adults enrolled into the HERO Kids Registry. In the 2nd half of 2023, 180 patient searches were conducted by emergency responders. By the end of 2023, 65 EMS agencies and four hospital emergency departments across Oregon had enrolled to use the Oregon Registries for EMS (OREMS) app. HERO Kids registrants reside in 23 of 36 Oregon counties, including two frontier counties and 21 rural ones. All urban centers are represented.

- During the same period, Oregon's HERO Kids Registry registrants identified eight different languages that they prefer to use to access the system and provide critical health details.[1]

- Oregon's Emergency Department Information Exchange (EDIE) generates an alert for providers when a patient matches a registrant in the HERO Kids Registry. EDIE alerts are available at all Oregon emergency departments. EDIE alerts vary by hospital and may show up in the ED patient track board, in the EHR, or by fax. 122 alerts were generated in the three months from October to December 2023.

**Key stakeholders said the following when the Kids of VALR program first deployed in Virginia:**

- *Steve Powell, EMS Chief of Rockingham County Fire Department, said*: "Emergency Services continually looks for ways to better serve their communities. The fire service has long been advocates of the pre-plan concept, which in a nutshell gives us an overview of what we are walking into with specific types of incidents before we physically arrive on the scene. When we discussed the idea of pre-planning for children with special needs or our underserved communities, I knew we had to be a part of this journey. Watching this program develop from a single idea to a multi-agency partnership has been incredible and the Rockingham County Department of Fire & Rescue is proud to be a part of this adventure. This program has the potential to change the lives of these children, their caregivers, and the providers tasked with answering their call for assistance."

- *Ashley Houff, Rockingham County Public Schools Supervisor of Pupil Personnel Services, said*: "Rockingham County Public Schools is honored to partner with local EMS staff to advertise and support our families with children having special medical needs. This collaboration allows our families access to the registry whereby responders are knowledgeable and privy of information specific to the precise needs of our youth to provide the best care possible."

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[1] In November 2023, for the KIDS OF VALR registry—a deployment of the R.U.S.H. Initiative for the Commonwealth of Virginia—BLT used an A.I. tool to translate the MEDIVIEW S.H.I.N.E. Registry interfaces into ten non-English languages.

In 2023 and 2024, federal funding was awarded to several communities—across California, Colorado, Michigan, New York, and Pennsylvania—and included with the project proposals were funds to support kick-starting local R.U.S.H. Initiate deployments within their communities as part of a focus on reducing roadway injuries and death, in light of the extraordinary danger that children and youth with SHNs face during and after a crash or other emergency on the road—from an inability to self-extricate, to the risk of becoming fearful and bolting onto the road. In 2024, BLT also signed an MOU with the largest public charter school in Washington, D.C., to bring the R.U.S.H. Initiative to the Nation's Capital.  Among the supporters of this program was Children's National Hospital.

**The R.U.S.H. Initiative's main evaluation metrics are: (1)** Enrollment by emergency responders and clinicians in facility-based care settings who are seeking to access the registry; **(2)** use of the system by emergency responders and facility-based care providers (e.g., in hospitals) to access patient's special health needs during emergencies. Additional metrics of interest include enrollment in the registry by patients and families, and contracts signed with financial supporters.  Enrollment by patients within a given period is not a primary focus because **(a)** there is a natural lag when it comes to building awareness of novel healthcare access points in underserved communities, **(b)** vulnerable communities often face a trust deficit associated with providing personal data into any registry or database, and this trust deficit is naturally overcome in time, and **(c)** rural communities in particular may not have a large number of patients—but with a small number of patients, in a small community the impact can be huge.

An important adjunct to our focus on adoption by Responders and Clinicians—who will actually use the system during emergencies—is the positive feedback loop known as a "network effect": as more Responders and Clinicians seek to use the system during emergencies, they become more likely to reference it to patients with SHNs and their families, which in turn builds trust.  This incentivizes more patients and their families to participate, which in turn makes it more likely to find patients in the registry and provide maximally informed care. The cycle persists.  Due to health privacy limitations, health outcome reporting may be limited after transfer to a hospital.

## COLLABORATORS AND PARTNERS

The R.U.S.H. Initiative is designed to empower the full range of stakeholders who care for patients with special health needs, including Fire, EMS & Public Safety professionals; Physicians, Nurses, and School and Occupational Nurses; and of course, Patients and their Families. Furthermore, the R.U.S.H. Initiative has no "age out" because when medicine makes magic happen, special health needs kids grow up to become special health needs adults.

| Practice Collaborators and Partners | | | |
|---|---|---|---|
| Partner/ Collaborator | How are they involved in decision-making throughout practice processes? | How are you partnering with this group? | Does this stakeholder have lived experience/come from a community impacted by the practice? |
| EMS, Fire, and Police | Emergency response agencies have been intimately involved in workflow, legal-regulatory and stakeholder feedback discussions, including as regards to budget and economics and operations | Emergency response agencies "of all patch colors" are not users of the technology and serve as liaisons to parents, schools, and participate in task force discussions and presentations, grant apps. | Yes – emergency responders have been vocal about their wish to know more details about the special health needs of young people who may need assistance during a healthcare crisis, disaster, public safety emergency, or even after a vehicle crash. |
| Parents, Patients, FANs, and Schools | Families and/or family representatives / councils and schools (depending on the community) have weighed in on everything from interface design to language requirements, to educational materials | Regular check-ins with families (as stakeholder groups), representatives on task force committees, and direct feedback (e.g., at conferences where the technology is being discussed). | Yes, parents are the primary care providers for the children receiving services from the program |

| | | | |
|---|---|---|---|
| Title V agency and/or Registry Partner (by geography) | Ensuring equitable access to critical health data in accordance with local laws and regulations (as applicable) and communicating the value of access for other stakeholders (e.g., hospitals, HIEs). | Co-development of educational materials; technology adjustment to meet local needs and priorities (e.g., around language, safety, security, etc.), and collaborative outreach (e.g., social media and webinars). | Responsible for regulation (if any) and representing the needs of the special health needs community to the broader healthcare ecosystem, government representatives, and grantmaking organizations (as appropriate). |

## REPLICATION

The R.U.S.H. Initiative is _specifically and intentionally_ structured to incorporate, from Day One, collaborators that include members of the regional public health, public safety, and healthcare ecosystems (including and especially where each of these crosses into areas that orient strongly toward families and young people with special health needs, such as schools).  This bent toward collaboration can slow the replication process because it compels the various stakeholders, who co-respond by design (a common phrase inside our company is "When the tones sound, everybody rolls"), to speak with one another and address respective strengths and shared deficiencies.

The deployment of the pediatric special health needs registry and Responder credentialing takes just a few days.  Thus, the methodical pace of program replication is not accidental—as the saying goes, "it is a feature, not a bug."  It takes time for Fire, EMS, and Public Safety agencies to schedule time together, and then to learn about one another's protocols and technical capabilities. There may be a preexisting political trust deficit across the agencies.  There is also a reasonable likelihood that regional schools have had minimal engagement with emergency responders outside the context of a training day, a visit to meet the students, or a regulatory matter (e.g., site inspection).  Yet, during an emergency—whether an individual has been injured, or a major weather or man-made disaster (e.g., active shooter) has transpired—Responders realize that each needs to know what the other knows.

After-action reports often cite information silos as a source of potential (or actual) injury, mortality and damage.  At the same time, each community is a bit unique; if those distinctions are disregarded, the program could fail on the rocks of cultural misunderstanding. Therefore, the R.U.S.H. Initiative aims to empower emergency responders, healthcare experts, schools, families, and patients to engage in dialogue about their own concerns.  This approach has already led to meaningful changes in program rollout, such as the elimination of home address capture where undocumented local residents might feel at risk, while balancing against the need for a city/state/ZIP to dispatch Responders appropriately.  It led to a prioritization of AI-powered translation in service of communities where many languages are in use.  The R.U.S.H. Initiative's technology, collaboration, and funding models are common, but the value of bringing stakeholders together for a shared purpose and an aligned lexicon cannot be overstated.

## INTERNAL CAPACITY

In addition to local clinical partnerships comprised of the R.U.S.H. Initiative's key stakeholders—Fire, EMS, Public Safety, Physicians, Nurses, School Nurses, Patients and Families—national participants in the R.U.S.H. Initiative include **Beyond Lucid Technologies**, which provides the program's technical infrastructure; **Thorne Ambulance**

**Service**, among the most admired ambulance services in America, which provides training and personnel support where they are needed to launch successfully; and the **DC Fire & EMS Foundation**, our national nonprofit partner.

In 2022, Beyond Lucid Technologies published a white paper elucidating the people, processes, and technical systems needed to raise and service an interoperable registry of critical documents that reflect the wishes and needs of seriously ill patients during an emergency. The goal was to clarify the minimum number of team members needed do so successfully with the premise that Fire, EMS & Public Safety professionals—at the patient's side—need immediate, on-demand, and *accurate* access but to a limited cache of data. There is zero margin of error for getting the information wrong or it being inaccessible so confidence, speed and simplicity are paramount to slash risk for all involved by reducing the chance of medical care being provided without context (that is, "doing the right thing but getting it wrong"). The white paper concluded that just 2-3 FTEs are needed to deploy such an interoperable registry, including one to serve as program's director—ensuring program sustainability, compliance, and serving as the registry's face to partner community organizations—and one (or more, as utilization grows) to oversee quality assurance and liaise with patients, families, responders, and clinicians regarding technical support.

It has long been clear that the R.U.S.H. Initiative, powered by BLT's MEDIVIEW S.H.I.N.E. Registry ["**S**pecial **H**ealth **I**nformation **N**eeds for **E**mergencies] should be locally anchored at a politically neutral organization like a public health or emergency medical services agency, a public university, a children's hospital, or a pediatric foundation to avoid even the perception of bias. In recognition of the fact that young people with complex care needs can face a medical emergency anywhere in the community—they might spend most of their time at home or at school, but they could be at a friend's house, church, mall, market, sporting event, etc.—we are committed to ensuring that no institution feels excluded from using our registry of SHN children and youth or engaging its local clinical partners. There should never be an instance in which *this* hospital, school or demographic cohort participates in the R.U.S.H. Initiative, and therefore *that* hospital, school, or cohort feels compelled to raise a separate repository.

## PRACTICE TIMELINE

| Phase: Planning/Pre-Implementation | | |
|---|---|---|
| **Activity Description** | **Time Needed** | **Responsible Party** |
| Execute a R.U.S.H. Initiative MOU | One week or less. The paperwork is simple – convening a discussion with the partners can take time. | Beyond Lucid Technologies in collaboration with local program stakeholders. |

The MOU lays out initial deployment partners and their responsibilities. The partners generally include Beyond Lucid Technologies (interoperable specialty care registry software), Thorne Ambulance Service (training), and the DC Fire & EMS Foundation (national nonprofit partner), plus a variable cadre of local clinical partners, including Fire, Emergency Medical Services (if separate from the Fire service), Public Safety (Police or Sheriff), and where possible, at least one school district. We also work to rally support from local pediatric leaders like children's hospitals, Emergency Medical Services for Children, and the Maternal and Child Health bureaus. The latter three serve as compelling sources of truth for patients and families.

The full slate of stakeholders listed above is not required to deploy the R.U.S.H. Initiative. There has been (and continues to be) substantial advocacy for a "bottom-up" approach to deploying the R.U.S.H. Initiative's combination of technology and clinical partnerships focused on high-risk young people during emergencies, because the public health, public safety and healthcare stakeholders are sensitive to the wishes of children and youth with special health needs and their families.

| | | |
|---|---|---|
| Convene the stakeholders | Subject to stakeholder scheduling | Beyond Lucid Technologies in collaboration with local program stakeholders (including the local deployment manager). |

Convening the stakeholders to codify local data validation rules, and associated graphical changes (i.e., to account for local culture, including linguistic translation requirements and Social Determinants of Health). For example, communities with a high rate of undocumented and/or underhoused residents may wish to avoid requiring patient and their families to list a home address in the registry; instead, the registry can be set up to present a city and state only (so the correct responder agency can be dispatches), or to list an alternate address such as a physician's office or a school instead of a specific home.

| | | |
|---|---|---|
| Community outreach to identify and engage early adopters | Months. But the process can begin immediately. In Virgnia, it started with just a single phone call: "Who wouldn't want to help these kids?" | Schools and parents' groups; public health and safety agencies public information officers (PIOs); hospitals; elected officials |

## Phase: Implementation

| Activity Description | Time Needed | Responsible Party |
|---|---|---|
| Stand up technical registry | One week | Beyond Lucid Technologies |
| Activate integrations to 3rd party technical systems (e.g., Emergency Department Information Exchange (EDIE), ePCR, health info exchange) | Variable based on the timeline required by the connecting vendor | Beyond Lucid Technologies with community partners (and their respective vendors) that convened and committed to making the local R.U.S.H. Initiative deployment successful. |
| Collect compliance documentation | Ongoing as patients register in the MEDIVIEW S.H.I.N.E. Registry and/or request to interoperate | Deployment manager(s) at the neutral local base of operations for the R.U.S.H. Initiative (e.g., a university or nonprofit organization) |

## Phase: Sustainability

| Activity Description | Time Needed | Responsible Party |
|---|---|---|
| Fundraising / Donations | Ongoing | Beyond Lucid Technologies, the DC Fire & EMS Foundation, local nonprofit partners |
| Technical maintenance and edits; New clinical stakeholders and integration partners training | Ongoing | Beyond Lucid Technologies, based on feedback from Responders, Clinicians, Patients and Families. Thorne Ambulance Service in support of local response agencies |

## PRACTICE COST

The R.U.S.H. Initiative partners an interoperable pediatric special health needs registry with local Responders and Clinicians to serve every parent, child, firefighter, medic, public safety officer, physician, nurse, and school nurse that is involved with a young patient's care during an emergency…**100% FREE, FOREVER**. We partner with regional nonprofits that are dedicated to protecting the aforementioned stakeholders, and their own financial supporters.

For interested organizations, the cost to support the R.U.S.H. Initiative is based on the number of young people in the covered community. The funds are paid through a regional nonprofit to ensure **(a)** the maximum tax benefit for the donor's generosity, and **(b)** that the nonprofit benefits and can continue to perform its excellent work. (Few nonprofits have "too much money.")  The local cost is derived from the U.S. Census QuickFacts, then adjusted by the pediatric proportion of the population (under 18, or another age if appropriate, e.g., Oregon uses 26 as a threshold to align with the Affordable Care Act).  This result is then multiplied by 20%, per the U.S. CDC estimate of children and youth with special health needs.  This count is multiplied by a per-child cost as low as $1 per month. **The targeted programmatic cost is $12 per child per year.**  Based on local needs, supplemental allocations may be sought to cover training, outreach through qualified partner organizations, and hiring a program manager who can be either a member of the local collaborative (for example, a school health services director), an employee of a mission-aligned regional nonprofit, or a Beyond Lucid Technologies team member assigned to the deployment.

| Budget | | | |
|---|---|---|---|
| **Activity/Item** | **Brief Description** | **Quantity** | **Total** |
| MEDIVIEW S.H.I.N.E. Registry | Fire/EMS interoperable registry of children and youth with special health needs. | Per child under coverage in the community (CDC est. 20% of children) | **As low as $12 per year ($1 per month)** |

| | | | |
|---|---|---|---|
| Responder protocol development and training | Training liaison for Fire, EMS, Public Safety, and Other Local Clinicians | One per deployment with follow-up as needed | **Estimated $50,000 per deployment** |
| Local deployment manager | Advocacy, community liaison/public relations, assistance with getting users signed up, etc. | 1-2 per deployment | **Estimated $50,000 per deployment but variable** *(I.e., based on whether deployment manager is in-house, a local partner, or a nonprofit team member)* |
| | | **Total Amount:** | **TARGET: $12 / child / year at no cost to patients, families, responders or clinicians.** Est. $100,000 in program-specific costs based on local needs. |

## LESSONS LEARNED

We have been gratified by the rapid and enthusiastic adoption of the technology-plus-clinical partnerships approach by emergency medical responders, other clinical stakeholders (e.g., physicians, nurses, school nurses), and patients and their families once they learn about the system's existence, function, purpose, and design. From one fire department, the program received deployment approval with a single phone call and a response by email that simply said, "Who wouldn't want to help these kids?" There has been an impression among community stakeholders—clinical, families, and otherwise—that they "cannot un-hear" about the availability and utility of the program, which brings stakeholders together in a way that they frequently have not. In Washington, D.C., a leading pediatric medical director said that his hospital is used to hearing about solutions focused on doctors, nurses, or families—and that they often sound similar, and they often lack efficacy data—but he had not before encountered a set of solutions and approaches that were so keenly focused on Responders themselves, in terms of data needs, usability/workflow, and legal-regulatory considerations.

That said, the unfortunate downside of so many "incomplete" or "point solutions" in the marketplace is that they lead to limited attention and create noise—which is to say that both patience, strong testimonials, and concrete non-anecdotal data are imperative to adoption. Even when schools, for example, want to advocate for solutions to assist patients with special health needs and their families, they need to find the right time during the year in which to do so: the start of a semester can be great because families are paying attention, but it also means that even more information is being presented to families at a time when they are already receiving so much—details can get lost.

Therefore, working with family advocates, parent liaisons from across the healthcare community, and repetition of messages about the value of heads-up awareness of special health needs, are all imperative. But most of all…patience to explain the value of providing pre-arrival information about young people's special health needs to Responders and Clinicians; and patience to answer lots of questions about how these patients' health data will be kept safe, secure, and only accessible to credentialed Responders during a bona fide emergency.

To facilitate system adoption, we would have earlier suggested that R.U.S.H. Initiative signatories build support and spur adoption by liaising with their state EMS data managers to establish a process that empowers the EMS

and/or Fire service—which has already cared for a patient with special health needs—to reach back out to the patient and/or their family, and to build awareness of the program and its benefits during an emergency.

The trust factor is already present with these patients and their families because the Responder agency previously cared for them. A safe and empathetic follow-up will help to underscore for the patient and/or their family that they are safe and part of a community—which in turns make them more likely to sign up and benefit from the R.U.S.H. Initiative's technology plus local care partners collaboration.

## NEXT STEPS

The technology behind the R.U.S.H. Initiative interoperates today with several leading technology and community care management systems—including PointClickCare's Emergency Department Information Exchange (EDIE), MyDirectives's advance care planning platform, and community resource navigation services from Unite Us, as well as health information exchanges across several states and a federally certified Qualified Health Information Network.  We are working with Fire & EMS electronic patient care record vendors to facilitate interoperability directly into ambulance-based charting systems, for more seamless data access besides a no-cost web app for use a phone or tablet (or a desktop at a hospital).  As noted above, federal funding was awarded in 2023 and 2024 to bring the R.U.S.H. Initiative to several additional states in 2025; and we have dialogues underway to deploy the R.U.S.H. Initiatives in association with schools and camps focused on Children & Youth with Special Health Needs.

## RESOURCES PROVIDED

- ASPR HHS Child and Adolescent Health Emergency Planning Toolkit
    - https://aspr.hhs.gov/at-risk/Pages/CYSHCN-planning-toolkit.aspx

- Beyond Lucid Technologies – Special Health Care Needs
    - https://www.beyondlucid.com/rush

- Callahan, James M, Steve Baldwin, Chelsea Bodnar, Susan Fuchs, Steven E Krug, Cynthiana Lightfoot, Mordechai Raskas, and Stuart T Weinberg. 2023. "Access to Critical Health Information for Children during Emergencies: Emergency Information Forms and Beyond." *Pediatrics* 151 (3).
    - https://doi.org/10.1542/peds.2022-060970

- Camp Burnt Gin
    - https://dph.sc.gov/health-wellness/child-teen-health/camp-burnt-gin/about-camp-burnt-gin
    - Interview conducted with Marie Aimone, Director, 30 June 2024

- CDC Children and Youth with Special Healthcare Needs in Emergencies
    - https://www.cdc.gov/disasters-and-children/special-healthcare-needs/index.html

- Census Bureau, QuickFacts
    - https://www.census.gov/quickfacts/

- Health Emergency Ready Oregon (HERO) Kids Registry
    - AMCHP Emerging Practice Page:
        - https://amchp.org/database_entry/health-emergency-ready-oregon-hero-kids-registry/
    - Program Overview via the Oregon Health & Science University:

- https://amchp.org/database_entry/health-emergency-ready-oregon-hero-kids-registry/

- *Journal of Emergency Medical Services* Announcement: "New Partnership Launched to Protect Children with Special Health Needs by Sharing Critical Insights During an Emergency"
    - https://www.jems.com/ems-management/new-partnership-launched-to-protect-children-with-special-health-needs-by-sharing-critical-insights-during-an-emergency/

- Kids of VaLR (Virginia Life Registry):
    - https://csems.org/rush.html