



Healing Healthcare

Connecting Data and Lived Experience
to Drive Meaningful Change

Erica Olenski, BCPA, FACHDM
VP, FINN Partners
Founder, August's Artists

eHealth Exchange™

Digital health experts meet on Twitter

NEWS

1 April 2010



Sarah Bruce



Europe's experts on the use of online engagement in healthcare are using microblogging site, Twitter, to set out a framework for using social media to put patients at the heart of Europe's healthcare systems.

The group, which is made up of more than 140 digital healthcare experts including e-patients and healthcare providers, aims to drive the adoption of social media and health 2.0 across the European healthcare sector.

It meets on Twitter every Friday to share current thinking and to discuss how to drive the movement forward.

However, after eight months and 30 online debates, the group has now met for the first time in the real world at an "unconference" in Berlin.

series.

HL7 STANDARDS

HEALTH

Engaging Conversations on
Healthcare and Technology

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AND THEN THERE WAS... #HITSM

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April 19th, 2011 by [Erica Olenski](#)

If you have used Twitter for health IT information in the last six months, it is likely that you have come across the hashtag “#HITsm” at one point or another. **The #HITsm hashtag stands for “health IT social media.”** Like other hashtags on Twitter that are search terms, or tags, dedicated to a specific topic or theme, #HITsm is dedicated to facilitating conversations on the use of social media in health IT.

It is likely you’ve seen the hashtag, and possibly even used it once or twice. But, **how exactly did it start and what types of conversations was it intended to facilitate?**

The philosophy behind #HITsm actually began long before Twitter. In fact, it originally began as the idea behind this blog, HL7 Standards around 2005. HL7 Standards, like #HITsm, was intended to be a resource for health IT professionals, connecting them to information, organizations and like-minded professionals in order to build a community of resources dedicated to solving some of the biggest challenges to date for the health care industry.



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Lessons in Change Management from Community Building

1. Be Consistent, Predictable & Reliable
2. Be Relatable; Get In the Weeds
3. Recognize Excellent Contributions Publicly
4. Lead through Service; Not Ownership

'TIS THE SEASON...2010 #HITSM AWARDS

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December 17th, 2010 by **Erica Olenski**

Last June, we published the [Top 10 Twitter Feeds to Follow for News on Healthcare IT](#). The health IT online community has grown substantially over the last 6 months. In light of that growth, we'd like to refresh the list with the official top #HITSm (health IT social media) accounts of the year.

Each of the following Twitter feeds comprise significant voices – individuals and organizations – involved in the development of and commentary on healthcare standards, policy, current events and debates that are defining the future of the healthcare IT industry. As social media leaders, they make up the foundation for the health IT information network on the Web and are shaping the future of health IT for all of those involved, from patients to providers and all in between.

HL7 Standards extended the opportunity to readers to submit nominations for the awards earlier this week. They were asked to consider nominees based on the following characteristics. Recipients of 2010 #HITSm Award should:

- Understand the health IT community and actively participate in healthcare IT conversations using social media tools.
- Create and/or republish (RTs) quality and relevant content.
- Engage with a noteworthy network of health care and health IT professionals and organizations.
- Encourage health IT professionals to engage in social media discussions.

 Print Friendly



Without further ado, the **2010 #HITSm Awards** go to... (*drumroll, please*)

Top Individual #HITSm Contributors:

- **@ej_butler** (Klout 71)
 - Twitter Bio: These are my tweets. Interested in Healthcare IT, Leadership, Organizational Change, Corporate Branding, Innovation, Agile Methods, Social Media & Coffee
 - Blog: N/A
- **@ahier** (Klout 70)
 - Twitter Bio: Passionate about healthcare, technology and government 2.0
 - Blog: <http://www.ahier.blogspot.com/>
- **@marxists** (Klout 70)
 - Twitter Bio: crazy about julie, tango and work, all encased by desire for God
 - Blog: <http://histalk2.com/category/ed-marx/>
- **@janicemccallum** (Klout 54)
 - Twitter Bio: Digital publishing expert and product strategist; focused on healthcare info (data analytics, research info, patient education, infodemiology). Tennis player.
 - Blog: <http://www.healthcontentadvisors.com/blog/>
- **@motorcycle_guy** (Klout 52)
 - Twitter Bio: Patient, Healthcare Standards Geek
 - Blog: <http://motorcycleguy.blogspot.com/>
- **@john_chilmark** (Klout 51)
 - Twitter Bio: IT analyst focusing on consumer-facing HIT. Fanatic cyclist, skier, happiest outdoors
 - Blog: <http://chilmarkresearch.com/>
- **@HITstrategy** (Klout 45)
 - Twitter Bio: Visionary, Passionate Health-Sciences IT Innovation Evangelist & Author – 'Health-Sciences Strategy' Blog. Opinions here are my own.
 - Blog: <http://www.healthsciencesstrategy.com/>

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REMEMBER YOUR STORY

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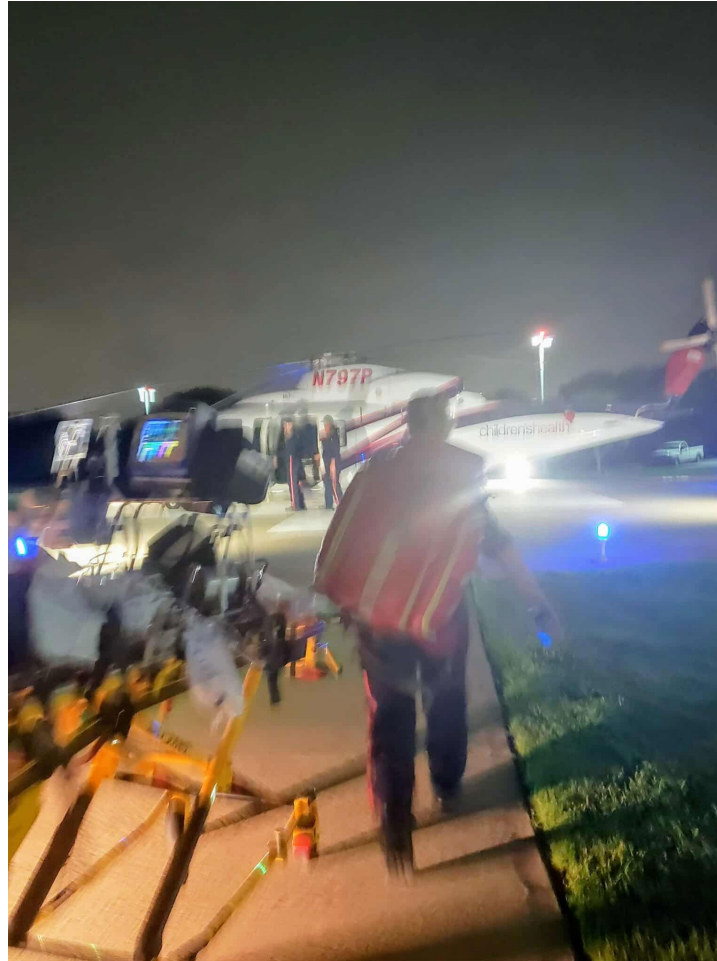
June 9th, 2011 by [Erica Olenski](#)

I fell in love with healthcare while working as a radiology technician aide at a well-known imaging center in Dallas during college. I was working late one evening with one of our senior technicians, when I realized the profound opportunity a relationship between health care and technology could provide.

Typically evening shifts were quiet and uneventful, which made them a great shift for doing homework and planning out my life after graduation. On occasion, a shift would be sprinkled with a STAT order or two for patients at a nearby hospital. This evening proved to be one of those occasional shifts when a STAT order for an MRI scan was called in.

What was particularly interesting about this order was that it was for an abdomen and pelvic scan for a woman who was 8 months pregnant. (For those concerned, MRI scans do not use radiation like a CT or x-ray scan and are [safe](#) within the third trimester.) As you can imagine, the radiology technician scanned images not only detailing the mother's injury, but as a by-product of the scanned location we were also given the most beautiful images of the infant.

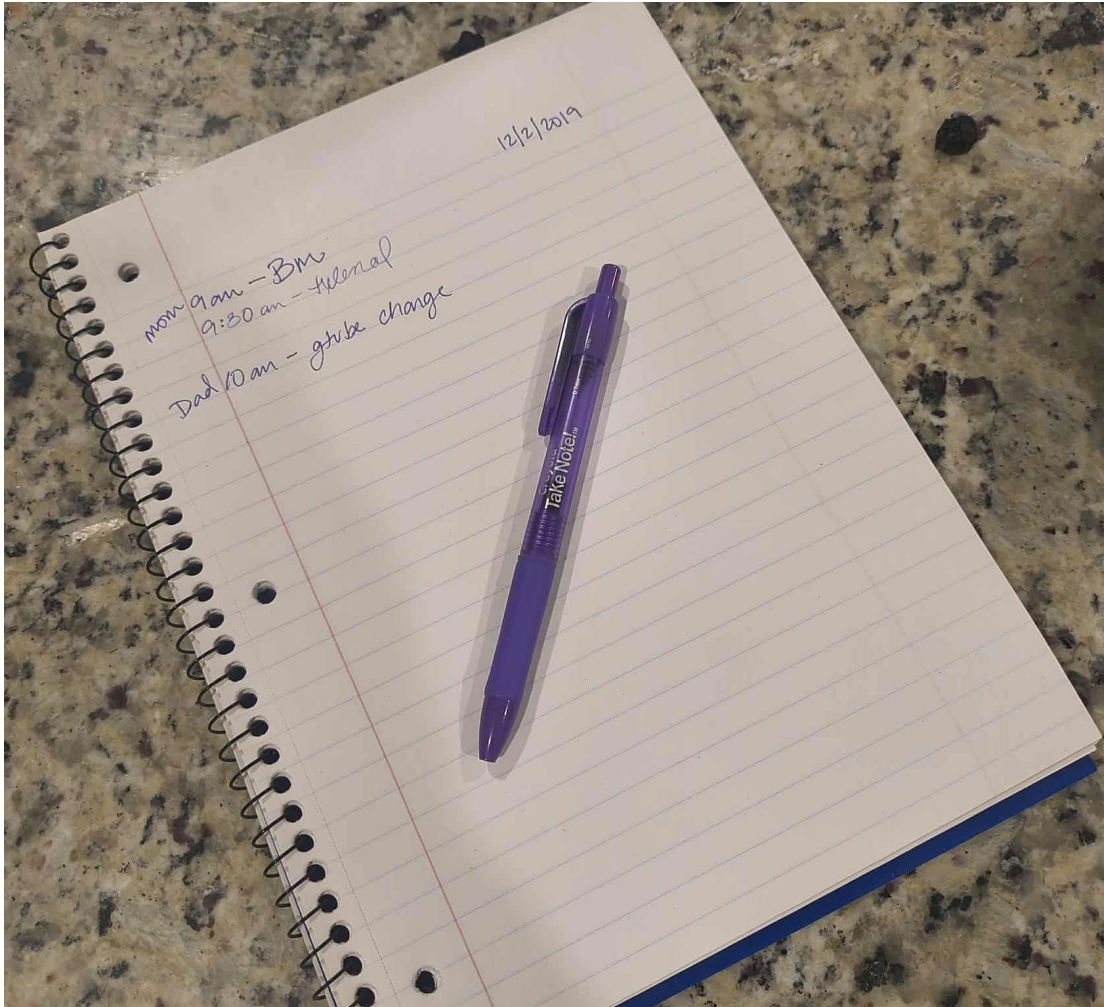





Lived experience isn't a bonus.

It's the blueprint.



ANNUAL
MEETING






Erica's Post

**Erica Olenski.**
November 16, 2019 · 🌐


ISO an app for managing medications and therapies (ideally for pediatrics) that can have multiple users. Almost like a light EMR for a single patient. TIA!—🇺🇸 looking for recommendations.



  Leslie Johnson, Marie DeStefano Vernon and 2 others


20 comments 2 shares

 Like  Comment  Share



Most relevant ▾


**Daniel Gracie**
Medisafe let me see if I can find the link for the full version for free for ya


5y  Like Reply Hide 

**Christina Lauren**
Manage how?


I used pill pack back in the day, not exactly an app but was effective for managing multiple medications. Only downside is they (at least back then) were not brand specific for OTC meds if that's something that affects you.


5y  Like Reply Hide 

 Christina Lauren replied · 2 Replies

**Kristi Driver Johansen**
Deana Watson can you offer any insight? Didn't know if you used something like this? TIA

5y Hide

 Kristi Driver Johansen replied · 1 Reply

**Jeremy Goslin**
Shameless plug for my current employer. Check out MyFHR. It can pull data from multiple EMRs and allows sharing (parents managing kids etc.). Maybe it meets your



QUALITY
LIVING

**CHILDREN'S HEALTH SYSTEM
OF TEXAS**

ROIF
CMC62523-010N0 Rev. 6/2022 Email: HM-Release-of-Information.FAX@childrens.com

Authorization for the Inspection,
Use, Disclosure and
Release of Health Information
Return Authorization to Fax: (214) 456-6170 OR
Email: HM-Release-of-Information.FAX@childrens.com

Place a patient label on all sheets

Location: _____

Patient Full Name: August Michael Johansen

DOB: 11/30/2018

MRN (for office use only): _____

CSN: _____

I represent that I am the patient or the patient's legally authorized representative (e.g. parent or legal guardian). This request for disclosure of health information is made at the request of the patient or the patient's legally authorized representative. I hereby request and authorize the Children's Health System of Texas ("Children's Health") to release the health information of the above named patient.

PURPOSE OF THE REQUEST / AUTHORIZATION (Please select one option):

☒ Continuation of Care ☐ Military ☐ Insurance ☐ School ☐ Personal ☐ Legal Purposes ☐ Social Security / Disability ☐ Other _____

PROTECTED HEALTH INFORMATION REQUESTED / AUTHORIZED FOR RELEASE

☐ Discharge / Death Summary ☐ Psychiatric / Psychological ☐ Photographs, Video, Digital / Audio ☐ History and Physical ☐ Operative / Procedure Report ☐ Alcohol / Substance Abuse D ☐ Clinic Note ☐ Immunizations ☐ Entire Hospital Record ☐ Consultation ☐ ECHO / Cardiac Cath on DVD ☐ Autopsy Report ☐ Reports: Labs, X-rays, Pathology, EKG, EEG, CT Scan ☒ Radiology Images on CD ☐ Other (Specify) _____

☐ Covering the period of healthcare from specific date(s) _____ to _____ OR ☒ All past, present, and future encounters *expires in 180 days as stated below

This health information may be disclosed or released to: Maria Heyerly, BSRT

Name of individual or facility _____

5050 Shornham Place, Ste 240 _____ San Diego _____ CA _____

Street Address _____ City _____ State _____

317-413-1353 _____ mheyerly@childrens.com _____

Telephone Number _____ Fax Number _____ Email Address _____

METHOD OF DELIVERY (electronic unless otherwise specified):

Select one:

☐ MyChart Patient Portal ☐ Fax ☒ Mail to the address above

☒ Email to the address above (☒ Encrypted or ☐ Unencrypted)

☐ Paper

☐ Pick up in person: _____ Best Contact Number: _____

SPECIALLY PROTECTED RECORDS

I understand that if my health record contains information in reference to alcohol / substance abuse, psychiatric / mental health care, HIV infection, or genetic testing, I agree to its release.

☒ I agree

☐ I do not agree, please specify (include appropriate dates): _____

TIME LIMIT, RIGHT TO REVOKE, RE-DISCLOSURE AND TREATMENT

Children's Health is hereby released from legal responsibility or liability for the disclosure of the records to the extent indicated and authorized by this authorization. I understand that I may revoke this authorization in writing at any time (except to the extent that action has been taken in reliance on this authorization) by sending a written notice to ATTN: Director Health Information Management Department, Children's Health, 1935 Medical District Drive, Dallas, TX 75235.

I understand that Children's Health may not condition treatment, payment, enrollment or eligibility for benefits on my completion of this authorization. I understand that this health information may no longer be protected by federal and state privacy laws once it is disclosed, and, therefore, may be re-disclosed by the recipient.

*Unless otherwise revoked, this authorization will expire 180 days from the date of my signature, or on this specific date (_____) or as of this specific event (_____).

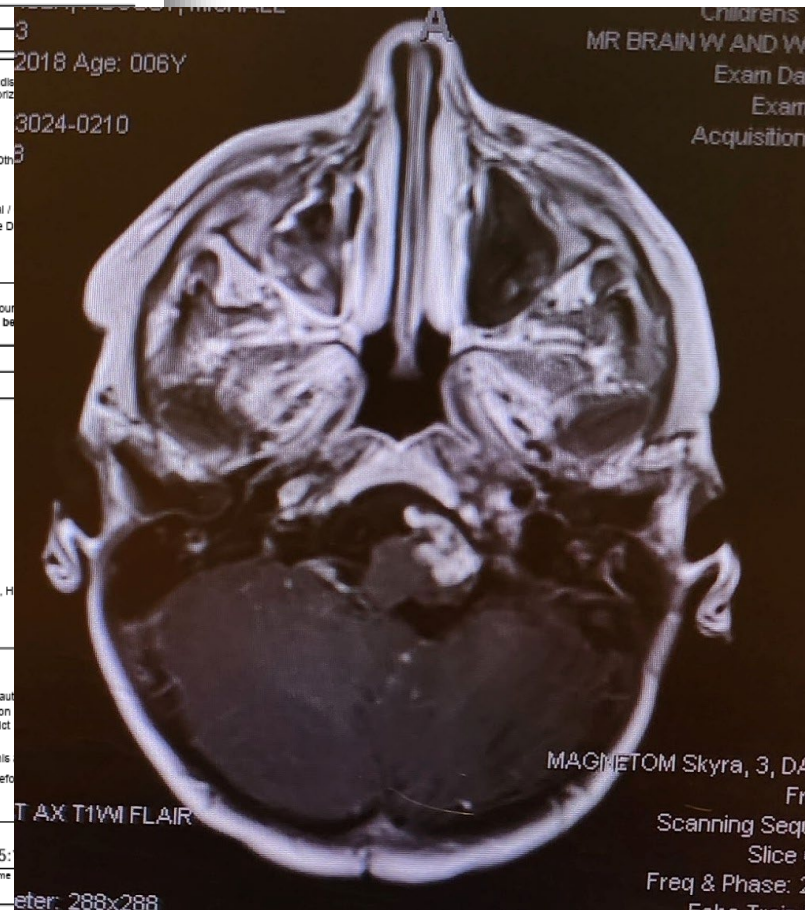
Erika Olenski _____ 05/19/25 _____ 05: _____

Signature of Patient or Legally Authorized Representative _____ Date _____ Time _____

Printed Name of Patient or Legally Authorized Representative _____ Relationship to Patient _____

IDENTITY VERIFICATION

Identity of requestor verified via: ☐ Photo ID ☐ Matching signature ☐ Other (specify): _____



Care Conference: August Michael Johansen

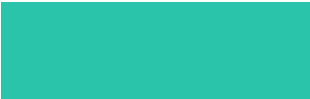
(DOB: 11/30/2018)

March 12, 2025

Children's Health - Dallas Campus

Attendees

Erica Olenski, August's Mom



Objectives

This care conference aims to align on treatment goals and explore every possible avenue for August's care. Our priority remains extending his life while preserving quality of life for both him and our family. Every treatment decision is guided by risk versus reward, ensuring a thoughtful, evidence-based approach while leaving no stone unturned.

We will review August's current treatment regimen for recurrent ependymoma, including a metronomic therapy protocol (excluding thalidomide), a ketogenic diet, and a range of adjunct therapies. Additionally, we will discuss potential treatment options informed by August's in vivo drug screening, FoundationOne report, and real-world data from the cancer innovation community at large. These options were evaluated for their ability to cross the blood-brain barrier, their safety in pediatric patients, and their alignment with our treatment goals.

A key focus of this meeting is collaboration and next steps. We need guidance on feasibility, sequencing, and clinical support for these treatment avenues, particularly regarding personalized vaccine development and its logistical considerations.

Your expertise is invaluable as we navigate this path. Thank you for your time and dedication to August's care.

Cancer Treatment Protocol

11/4/24 through current, 3/12/25)

thalidomide): <https://pubmed.ncbi.nlm.nih.gov/24123865/>

(high fat, high protein)

1, RSO) (2.5-5mg, Q4h)

<https://www.amazon.com/dp/B09GSHKTMG/>

<https://www.amazon.com/dp/B0BNW2DYCN/>

<https://www.amazon.com/dp/B0BWK3KG7R/>

<https://www.amazon.com/dp/B0BWK3KG7R/>

<https://www.amazon.com/dp/B0BWK3KG7R/>

body, 10 minutes QD

rt - 10 minutes QD

ment Options for Discussion

ted by multiple data sources, including an in vivo drug
oston Children's Hospital, the FoundationOne report from
orld data insights from [CancerX](#). CancerX is a community of
who are actively aware of August's case and engaged in
appropriate. Additionally, tumor tissue from his May 2024
analysis or future testing.

tering were identified through a comprehensive analysis of
ential therapy—thalidomide, vorinostat, everolimus, and a
ferenced to the best of our ability for permeating the
asonable safety profile in pediatric patients. Our discussion
and the expected impact on treatment effectiveness and
ily.

re additional perspectives and ideas, provided they align
pediatric safety, and meaningful potential benefit. If other
standards, we welcome input to ensure we consider all viable

ment Options for Discussion

m current regimen
sin Barrier (BBB): Limited evidence; less commonly used for

ry and anti-angiogenic properties
S tumors due to limited BBB penetration
uation to determine its potential role in the metronomic

ng to therapy based on expert input

in treatment
sin Barrier (BBB): Yes, has shown promise in treating

ings, though specific quality-of-life (QoL) data is limited
ed; common side effects include nausea, vomiting, and
ilities (typically transient and manageable)
ncing tumor response through epigenetic modulation
access via compassionate use

in treatment
sin Barrier (BBB): Yes, has been used in CNS tumors

ed in pediatric populations
include stomatitis, respiratory infections, and

itoring for metabolic and immune-related effects
s other targeted therapies
options and potential integration into treatment

mor block (can request from Boston)
data (4-digit class I & II)
ncing of high-purity tumor tissue (200M 150bp paired-end
at)
ordinated with August's oncology team

accine to train the immune system to target tumor-specific

d in Europe under an "individualized healing attempt" or
ngle-patient IND request
.000 for development and production
dination with other treatments due to immune system

support for IND request
or block transfer and sequencing logistics
g of vaccine within treatment plan to optimize immune

JOHANSEN AUGUST, this is Wellpoint, and we have been trying to reach you to schedule your Annual Wellness Visit. Please contact us at (888) 773-8994 at your earliest convenience. Reply STOP to unsubscribe. Msg&Data rates may apply

1:19 PM



Erica Olenski, BCPA, FACH... • You
Award-winning BCPA + healthcare comms str...
1mo • Edited •



Make it make sense.

Today I received this text, nearly three months after my son August passed away.

This is why trauma-informed care must include the caregiver experience. An unsubscribe will not teach the system what went wrong. Learning requires intention, ownership, and cross-functional design.

Where healthcare communications leaders can help:

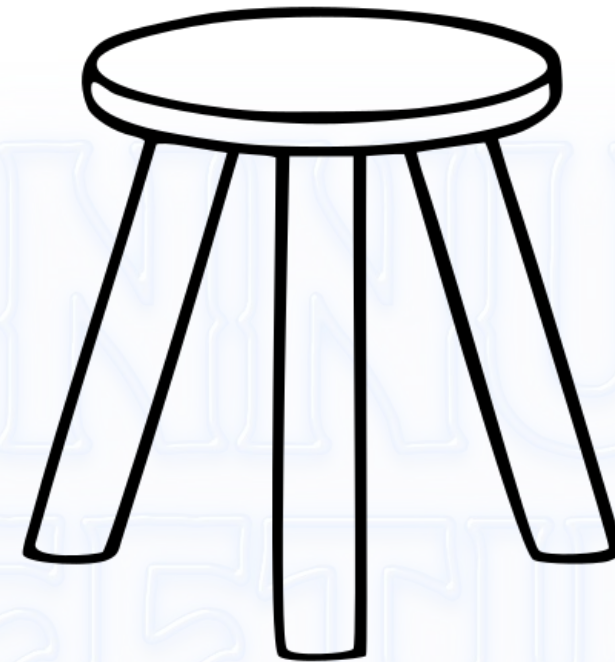
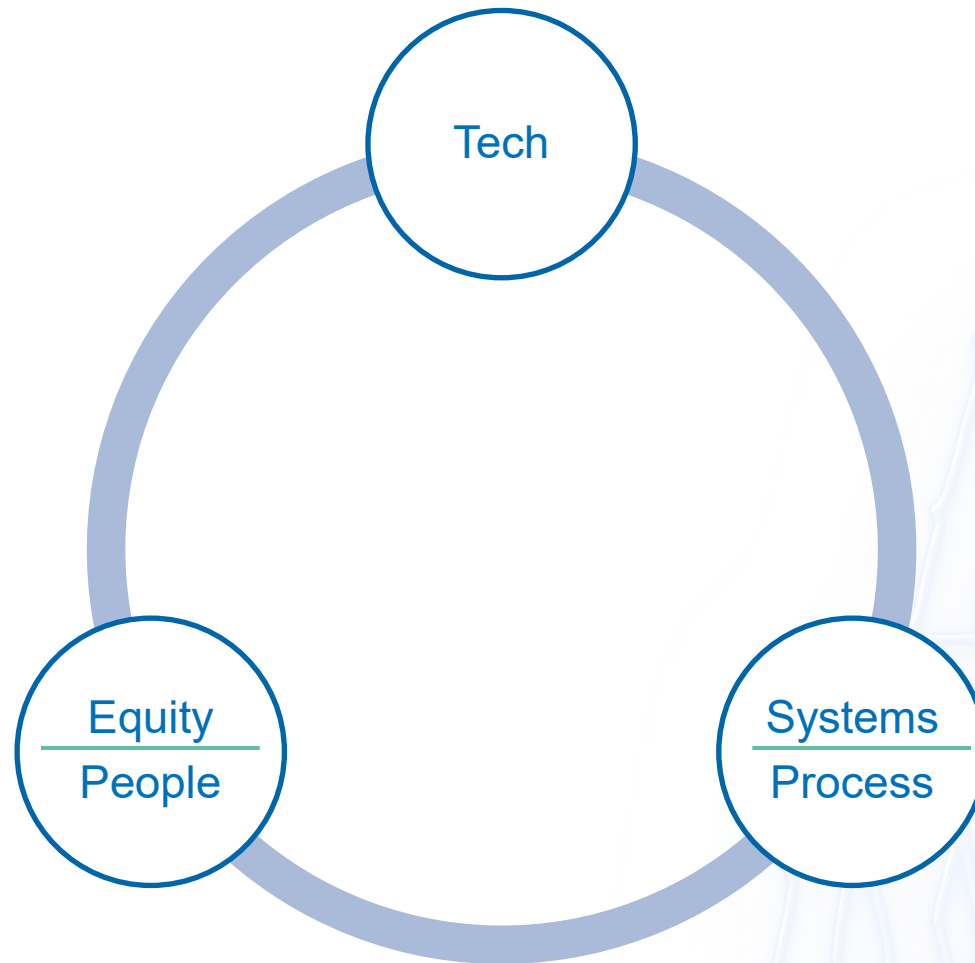
- ✦ Partner with clinical, IT, and CX teams to set bereavement flags and stop all outbound messages immediately across vendors and channels.
- ✦ Build communications rules for critical life events, including language, timing, and opt-out safeguards for caregivers.
- ✦ Test journeys with bereaved caregiver personas and empower frontline staff with clear escalation paths. (By the way, we did receive a sympathy card from **Wellpoint** after August passed away which was nice, so beyond clinical indicators, I know they know what happened.)
- ✦ Measure what matters beyond open rates: harm avoidance, sentiment, and caregiver trust.

Health outcomes are more than compliance with care plans or perfectly timed reminders. Outcomes are shaped by how we talk to people and how we honor

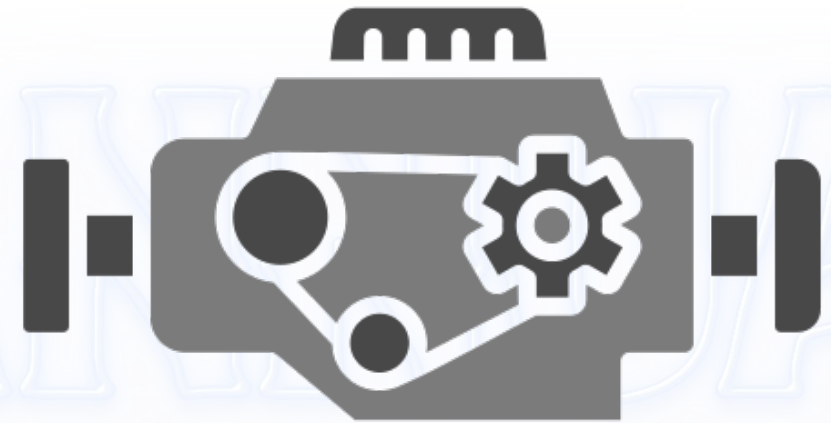
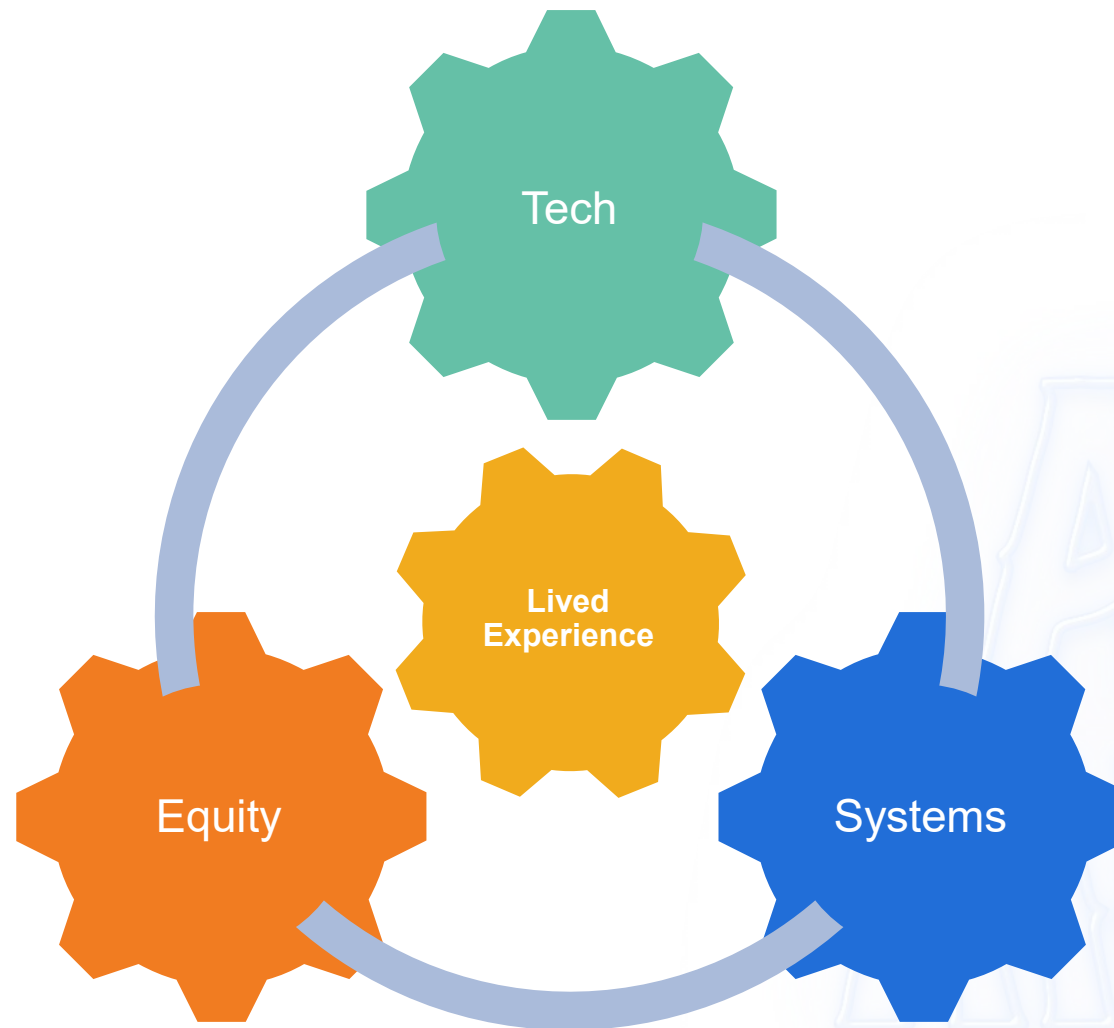
To date, innovation has remained “point-to-point.”

The system fails when it can't hold accountability.

Current State Innovation Framework



Human-Centered Innovation Engine



Begin with lived experience, not hypothetical scenarios.

Don't shy away from complexity; it makes systems, technology, and equity programs stronger.

Trauma-informed care isn't optional.

What is Executive Function?

Executive functions or self-regulation serves as the foundation for life-long functioning in such areas as critical thinking and problem-solving, planning, decision making and executing tasks. Executive functions or self-regulatory capacities are the building blocks for a range of important skills. These skills mature at different rates and develop over time (Diamond, 2013; Jones, 2016; Zelazo et al., 2016). Working memory and self-control are among the first set of executive functions that develop (typically during the early childhood), setting the stage for attentional capacities and goal directed behavior during the pre-teens years, better planning and refined goal-directed behavior during adolescence, and more efficient problem-solving, decision making and cognitive flexibility in adulthood.

The experience of trauma, especially when it is prolonged, can disrupt executive functioning skills. Children who have experienced prolonged or pronounced stress and adversity, including poverty and trauma experiences, may struggle more than other children do to regulate their thoughts, feelings, and behaviors (Murray et al., 2015; Zelazo et al., 2016). Severe childhood stress appears to have lasting effects, with executive function or self-regulation related difficulties seen into adulthood. In addition, adolescents who report having experienced trauma, such as maltreatment or exposure to a parent's intimate partner violence, have been found to be less effective than

their peers
by adverse
impulse

Why the Concept of Executive Function is Important to Human Services

Executive functions involve regions of the brain associated with information processing, (including such functions as attention and working memory), regulating emotions and behavior (including such functions as impulse control and suppressing inappropriate responses), and even creativity and some aspects of personality. (Diamond, 2013; Zelazo et al, 2016). Individuals who have problems with executive functions in childhood or adulthood may have difficulty with social appropriateness, planning projects, working independently, remembering details, paying attention, or starting and completing tasks.

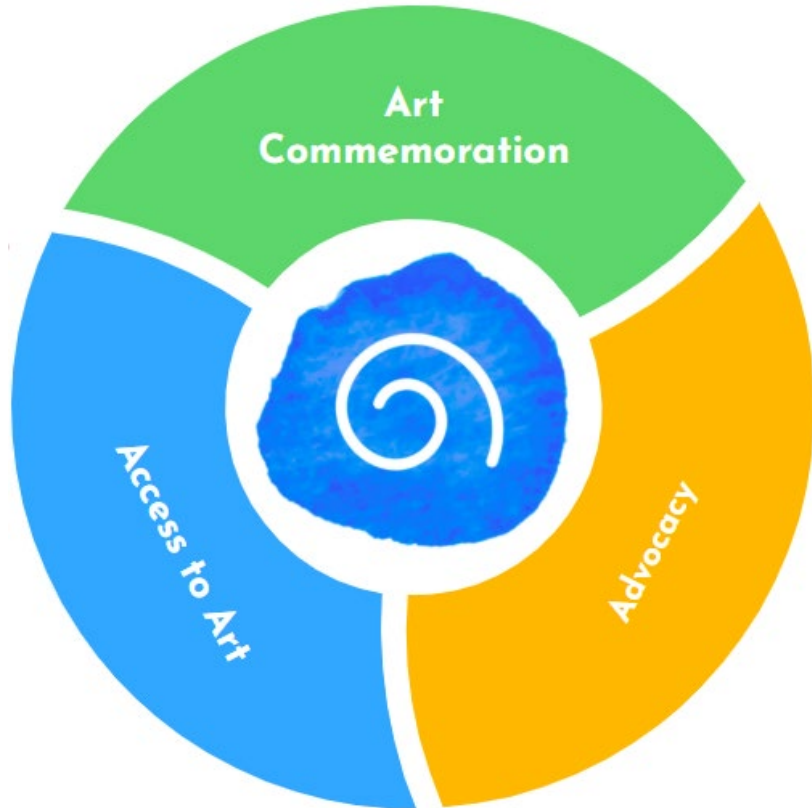
“The Triphasic Model for Treating Trauma”

Phase 1: Safety and Stabilization

Phase 2: Remembrance and Processing

Phase 3: Integration, Reconnection, and Rehabilitation





AUGUST'S ARTISTS

Coloring happiness & healing.



August's Artists is focused on serving pediatric healthcare **patients, their families, and caregivers** by providing consistent **access** to window crayons, commemorating their **artwork** as a way to celebrate some of the most formative and impactful moments in life, and meaningful **advocacy** for *trauma-informed, family-centered, and whole-person care*.

We believe that every child, family, and caregiver deserves access to art as a way to find **peace** during stressful healthcare experiences, the **ability to celebrate** and commemorate health milestones, and the **support to heal**.

The window crayon donations



The art commemoration

From hospital window...



to keepsake poster!

Innovation ≠ Technology Only

Complex Patients = Use Case Gold

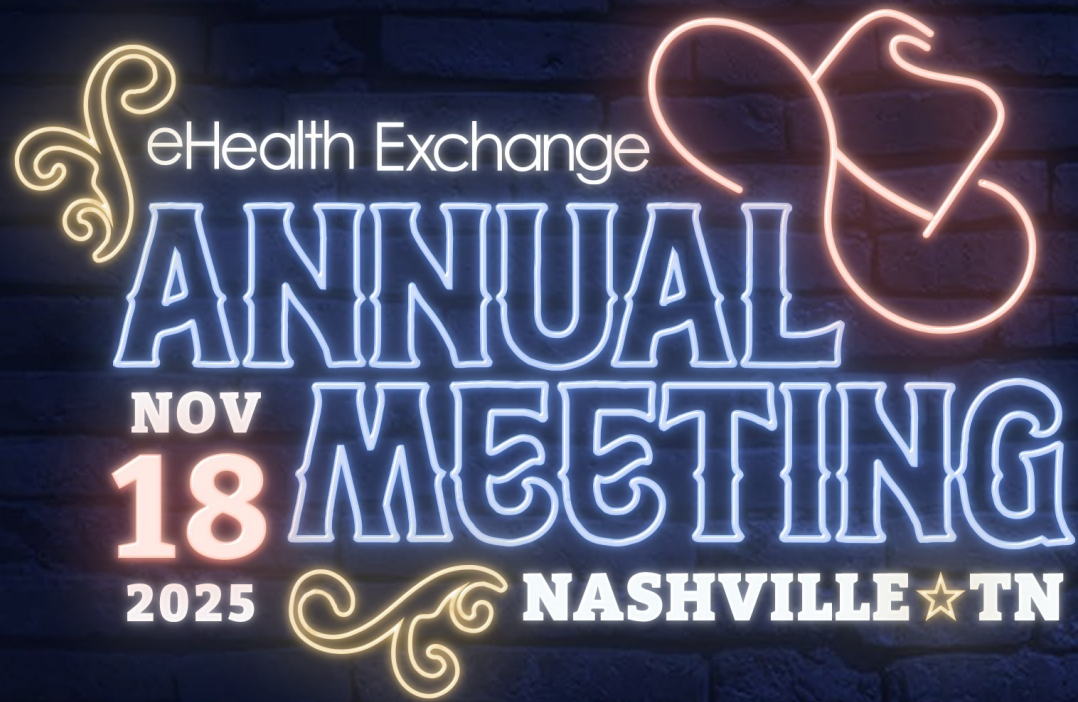
Don't Kill the Caregiver

Stories Heal

ANNUAL
MEETING



In loving memory of
August "Auggie" Johansen
11.30.18 – 6.26.25



eHealth Exchange™

Thank you for your participation.

BeMyQHIN.com