Partnering with Patients for Improved Diagnosis

“What Ifs”

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Society to Improve Diagnosis in Medicine (SIDM)

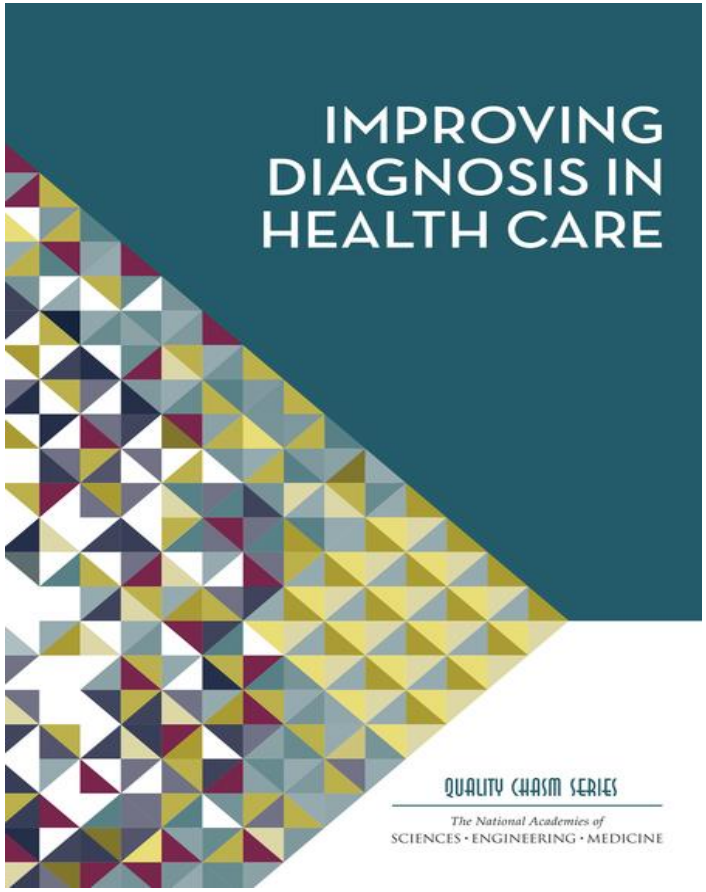
SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

Impact of Diagnostic Error
National Academy of Medicine (NAM)

Diagnostic errors affect more than 12 million adults in outpatient settings each year

40,000-80,000 die each year from diagnostic failures in U.S. hospitals alone.

Every 9 minutes someone in a US hospital dies due to a medical diagnosis that was wrong or delayed.



NAM definition: What is a Diagnostic Error?

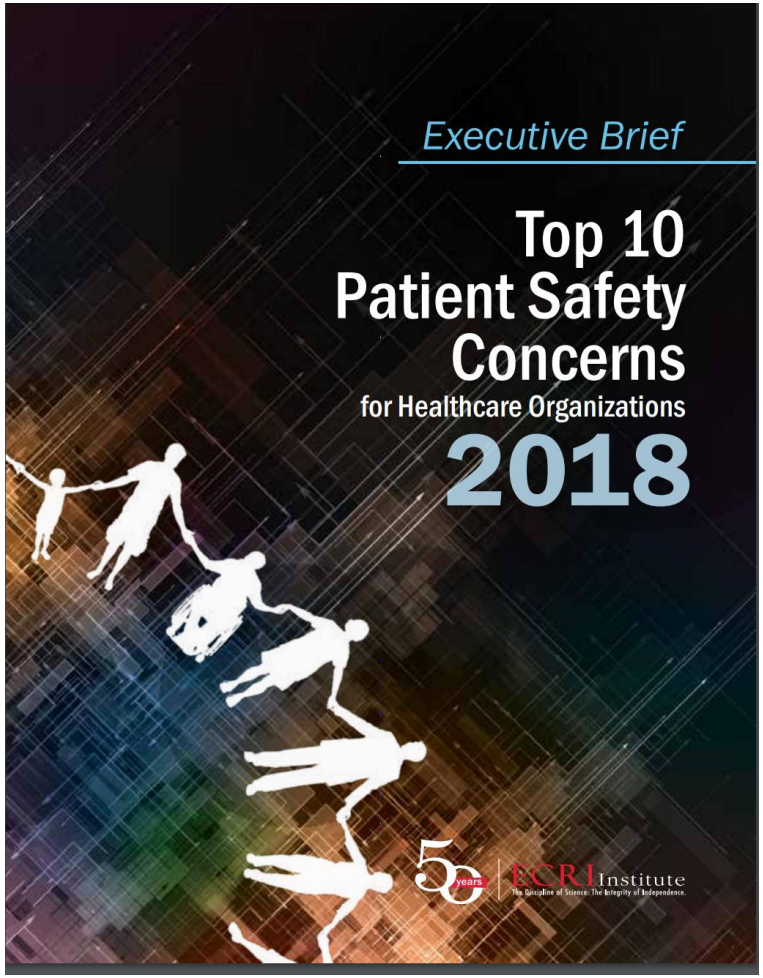
The failure to:

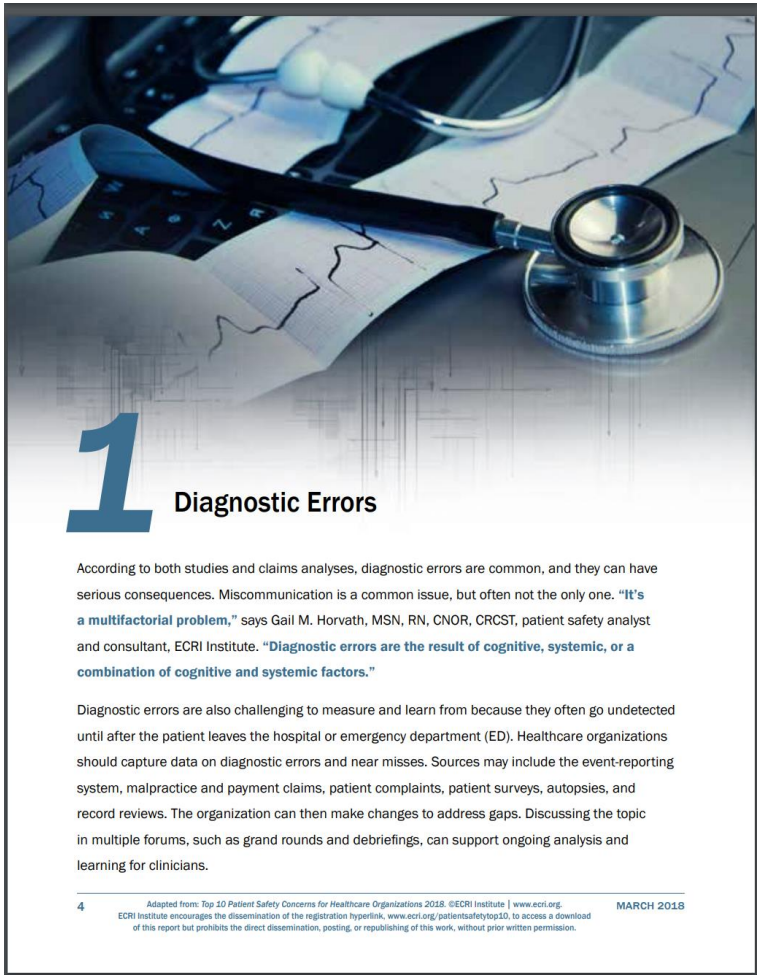
(a) establish an **accurate** and **timely** explanation of the patient's health problem(s)

or

(b) **communicate** that explanation to the patient

ECRI: DxE is #1 Patient Safety Concern (March 2018)



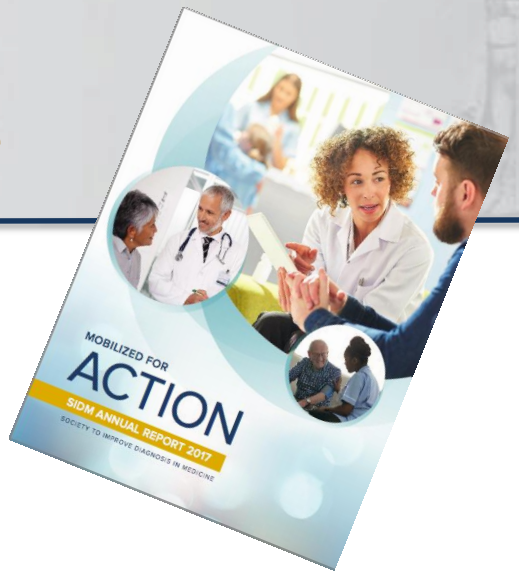


1 **Diagnostic Errors**

According to both studies and claims analyses, diagnostic errors are common, and they can have serious consequences. Miscommunication is a common issue, but often not the only one. **"It's a multifactorial problem,"** says Gail M. Horvath, MSN, RN, CNOR, CRCST, patient safety analyst and consultant, ECRI Institute. **"Diagnostic errors are the result of cognitive, systemic, or a combination of cognitive and systemic factors."**

Diagnostic errors are also challenging to measure and learn from because they often go undetected until after the patient leaves the hospital or emergency department (ED). Healthcare organizations should capture data on diagnostic errors and near misses. Sources may include the event-reporting system, malpractice and payment claims, patient complaints, patient surveys, autopsies, and record reviews. The organization can then make changes to address gaps. Discussing the topic in multiple forums, such as grand rounds and debriefings, can support ongoing analysis and learning for clinicians.

A Focused Effort Was Needed: SIDM Society to Improve Diagnosis in Medicine



VISION

Creating a world where no patients are harmed by diagnostic error.

MISSION

SIDM catalyzes and leads change to improve diagnosis and eliminate harm, in partnership with patients, their families, the healthcare community and every interested stakeholder.

Strategic Priorities

Make improving diagnosis a strategic priority for healthcare.

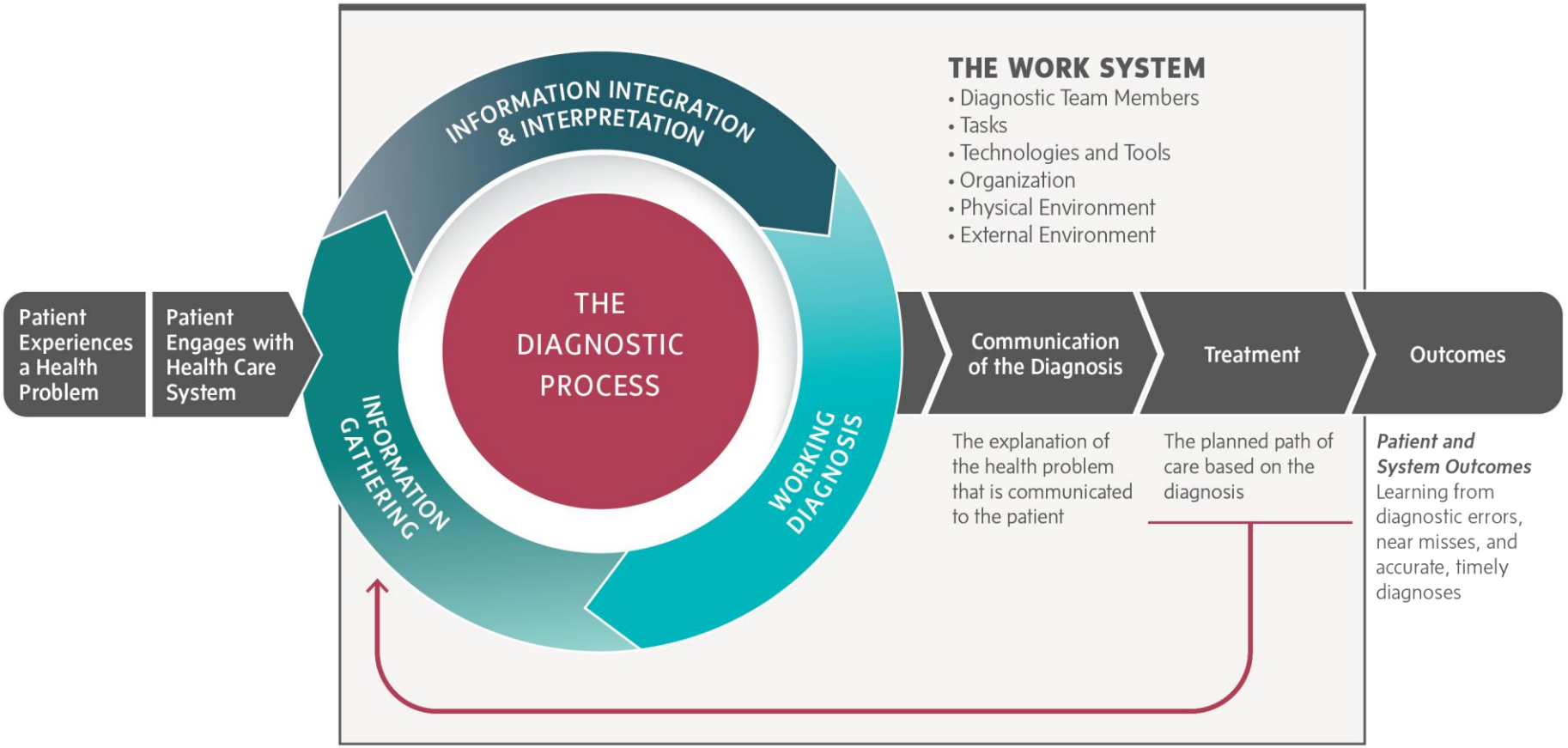
Advance research on diagnostic accuracy and error.

Transform professional medical education and develop new leaders.

Improve diagnostic performance in current clinical practice.

Engage and integrate patients and their families and all diagnostic improvement efforts.

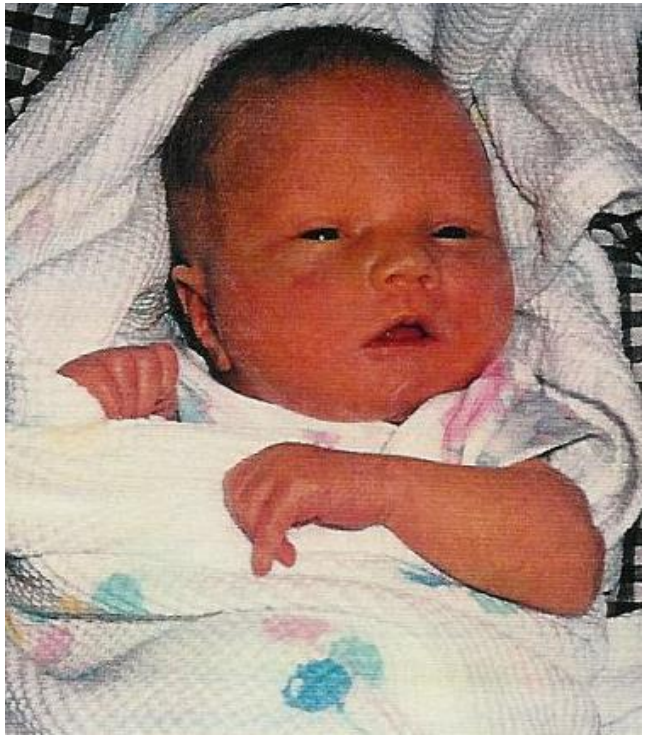
National Academy of Medicine's Diagnostic Process



The National Academies of SCIENCES • ENGINEERING • MEDICINE

SOURCE: National Academies of Sciences, Engineering, and Medicine. 2015. *Improving Diagnosis in Health Care*. Washington, DC: The National Academies Press.

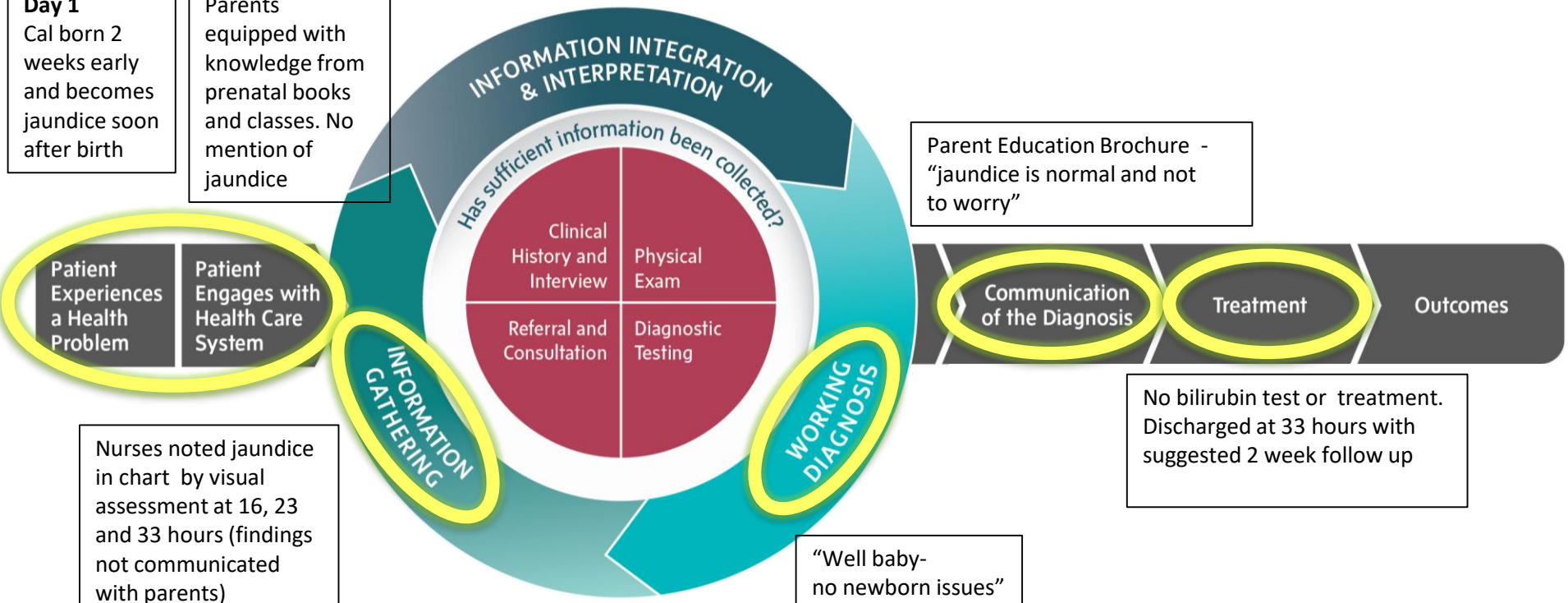
Case Study #1 - Cal Sheridan:
Failure to diagnose severity of newborn jaundice resulting in Kernicterus



Cal's Diagnostic Journey - Day 1

Day 1
Cal born 2 weeks early and becomes jaundice soon after birth

Parents equipped with knowledge from prenatal books and classes. No mention of jaundice



Parent Education Brochure - "jaundice is normal and not to worry"

Nurses noted jaundice in chart by visual assessment at 16, 23 and 33 hours (findings not communicated with parents)
No bilirubin/jaundice test.

"Well baby- no newborn issues"

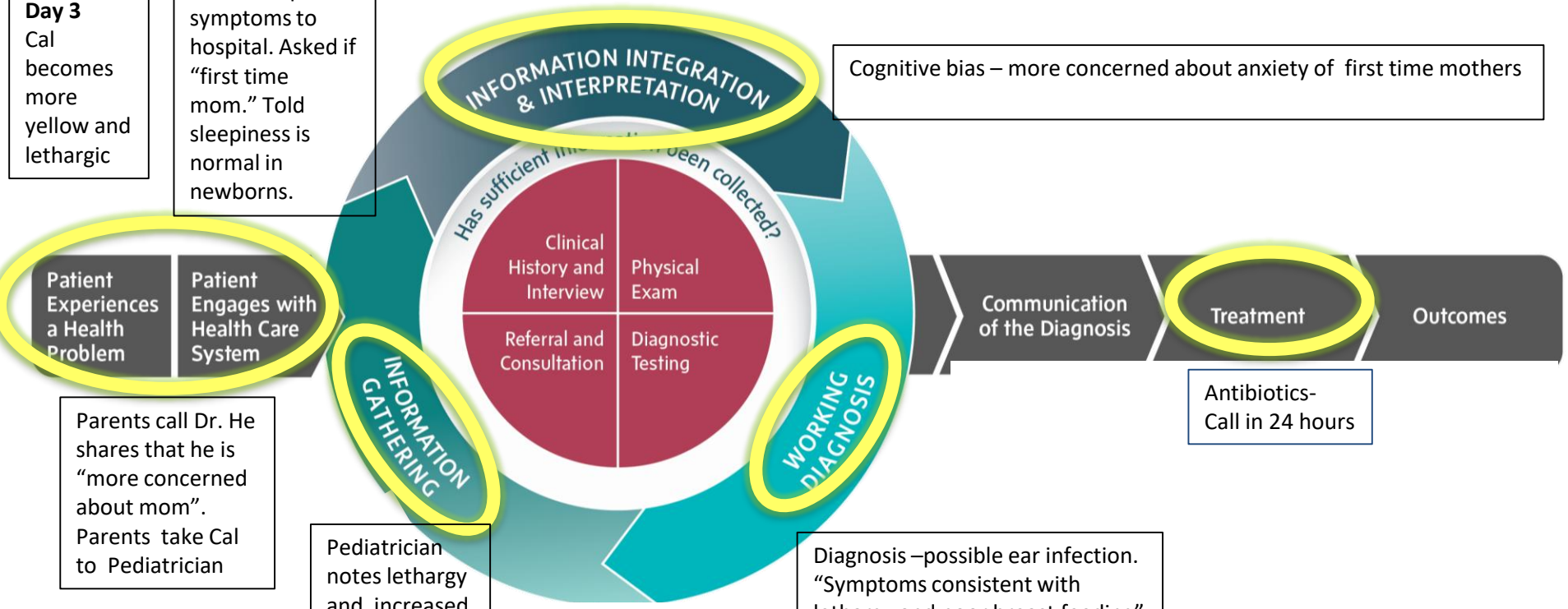
No bilirubin test or treatment. Discharged at 33 hours with suggested 2 week follow up

SOURCE: National Academies of Sciences, Engineering, and Medicine. 2015. *Improving Diagnosis in Health Care*. Washington, DC: The National Academies Press.

Cal's Diagnostic Journey – Day 3 (Outpatient)

Day 3
Cal becomes more yellow and lethargic

Parents report symptoms to hospital. Asked if "first time mom." Told sleepiness is normal in newborns.



Cognitive bias – more concerned about anxiety of first time mothers

Parents call Dr. He shares that he is "more concerned about mom". Parents take Cal to Pediatrician

Pediatrician notes lethargy and increased yellow color by visual assessment. No bilirubin test ordered

Diagnosis –possible ear infection. "Symptoms consistent with lethargy and poor breast feeding"

Antibiotics- Call in 24 hours

SOURCE: National Academies of Sciences, Engineering, and Medicine. 2015. *Improving Diagnosis in Health Care*. Washington, DC: The National Academies Press.

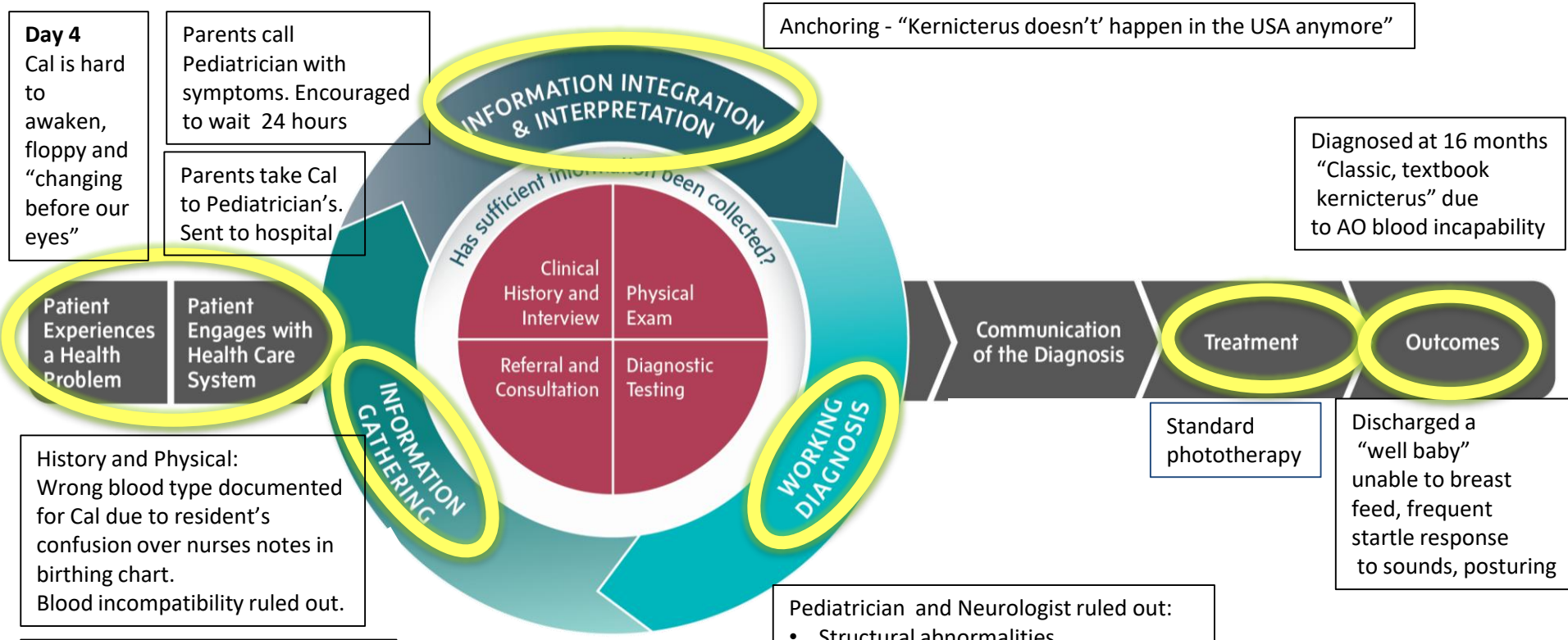
Cal's Diagnostic Journey – Day 4 (Readmission)

Day 4
Cal is hard to awaken, floppy and "changing before our eyes"

Parents call Pediatrician with symptoms. Encouraged to wait 24 hours

Parents take Cal to Pediatrician's. Sent to hospital

Anchoring - "Kernicterus doesn't' happen in the USA anymore"



Diagnosed at 16 months "Classic, textbook kernicterus" due to AO blood incapability

Standard phototherapy

Discharged a "well baby" unable to breast feed, frequent startle response to sounds, posturing

History and Physical:
Wrong blood type documented for Cal due to resident's confusion over nurses notes in birthing chart.
Blood incompatibility ruled out.

Bilirubin test: 34.6 mg/dcl-highest ever recorded at that hospital.
Test repeated twice for accuracy
No referral to NICU

Pediatrician and Neurologist ruled out:
- Structural abnormalities
- Meningitis

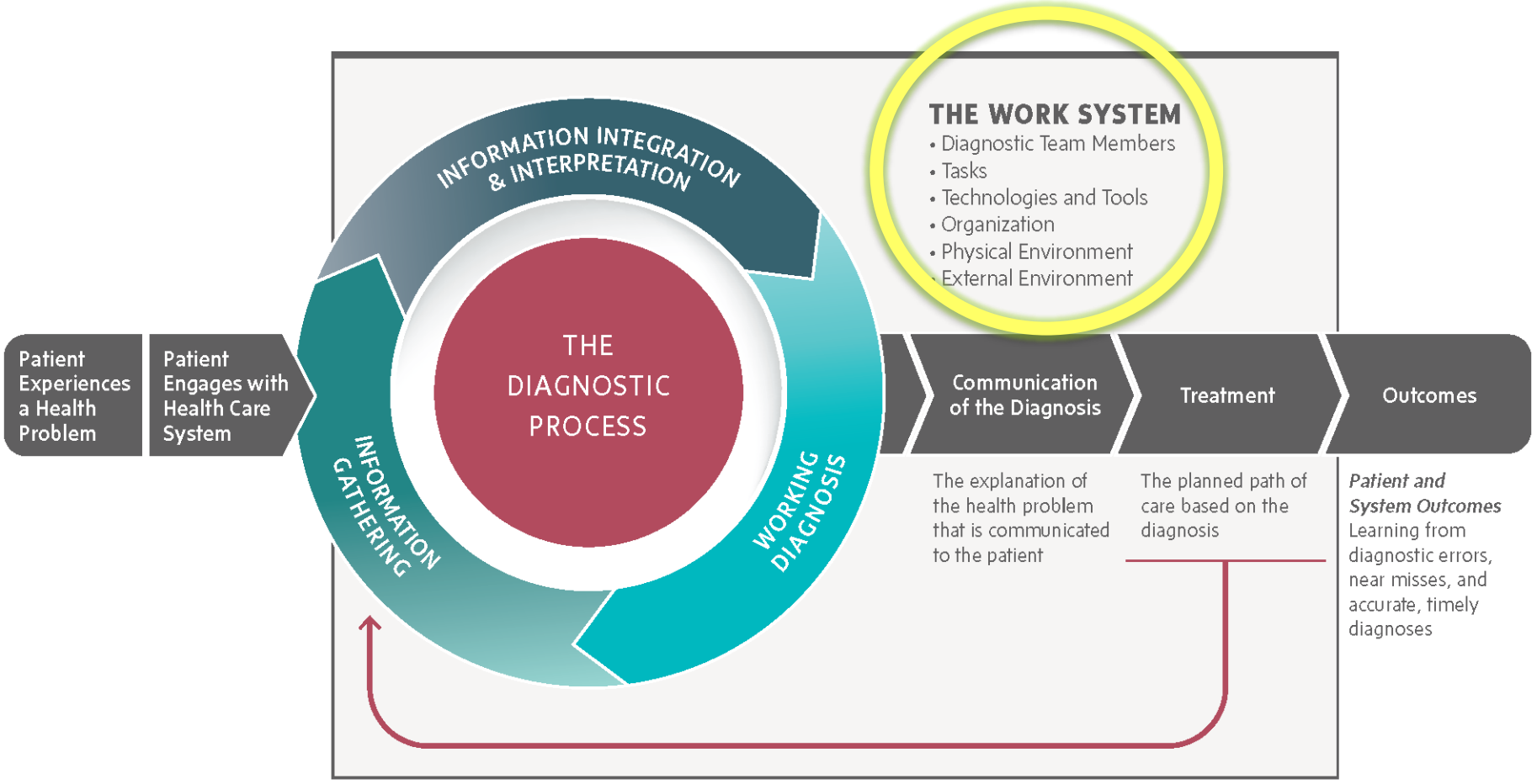
Kernicterus never in differential diagnosis

Dr's. notes:"Opisthotonis and high pitched cry" - requested Neuro consult per parents request
MRI: increased intensity in Globus Pallidus - not communicated to parents

SOURCE: National Academies of Sciences, Engineering, and Medicine. 2015. *Improving Diagnosis in Health Care*. Washington, DC: The National Academies Press.

Where Failures in the Diagnostic Process Occur

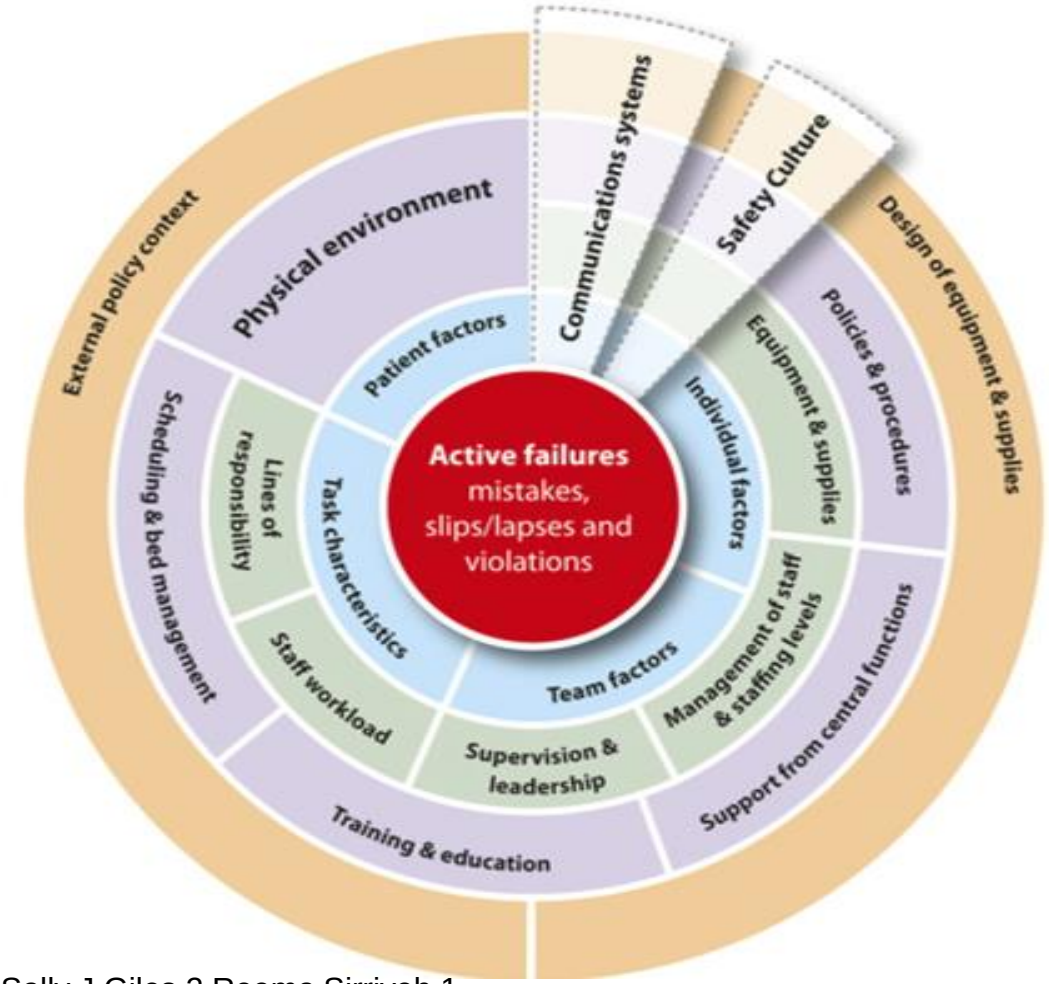
- Failure of Engagement
- Failure in Information Gathering
- Failure in Information Integration
- Failure in Information Interpretation
- Failure to Establish an Explanation for the Health Problem
- Failure to Communicate the Explanation



The Work System

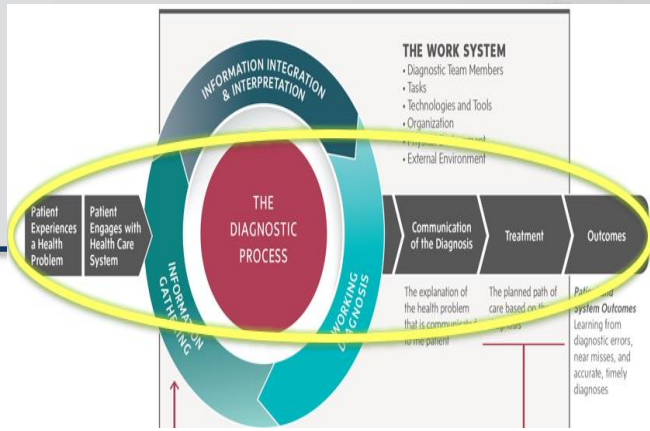
Factors contributing to Cal's diagnostic error

- **Policies and procedures**
- Support from central function
- **Training and education**
- **Scheduling and bed management**
- Lines of responsibility
- Staff workload
- **Supervision and leadership**
- **Management of staff and staffing l**
- Equipment and materials
- **Patient factors**
- Team factors
- **Individual factors**
- Task characteristics
- **Communications systems**
- **Safety culture**
- External factors



Rebecca Lawton,1 Rosemary R C McEachan,2 Sally J Giles,2 Reema Sirriyeh,1 Ian S Watt,3 John Wright2 BMJ Qual Saf 2012;21:369e380. doi:10.1136/bmjqs-2011-000443

“What If’s – Engagement



- Hospital pre-admission and discharge information included information on risk factors, the dangers of severe jaundice, the symptoms to report, to whom and by when and how to escalate if no action to get an accurate and safe diagnosis?

- I had been empowered as a member the “diagnostic team” and that my concerns and the symptoms that I was reporting had been integrated into the “information gathering” to help form the diagnosis?

- I had access to electronic health records (EHRs), including real time clinical notes and diagnostic testing results, to enable me to participate in the diagnostic process and review the health records for accuracy?

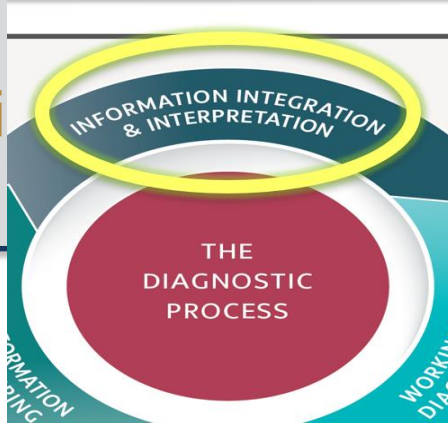
“What If’s” – Information Gathering

- The nurses had been considered “frontline” diagnostic team members and were authorized to order or administer a bilirubin test?
- Clinical staff had adhered to hospital policy of delivering newborn care based on the AAP guidelines on jaundice management – *“Measure the total serum bilirubin (TSB) or transcutaneous bilirubin (TcB) level on infants jaundiced in the first 24 hours”.*
- There had been a systematic universal bilirubin/jaundice test done on all newborns prior to discharge instead of relying on visual assessment?

What if upon readmission:

- There had been standardized nomenclature to document newborn blood type?
- What if there had been adequate supervision and support for the resident?
- The lab technician and radiologist had been part of the “diagnostic team” and had 2 way communication with the treating clinicians and Pat and me?

“What If’s” - Information Integration and Interpretati



- Clinical reasoning had not been influenced by biases including the concern about anxiety and first time mothers and the clinician’s belief that kernicterus had been eradicated and did not happen any more in newborns in the USA?

- Young doctors and nurses unfamiliar with the effects of severe jaundice had been trained on identifying risk factors for severe jaundice and effective ways to diagnose and treat severe jaundice?

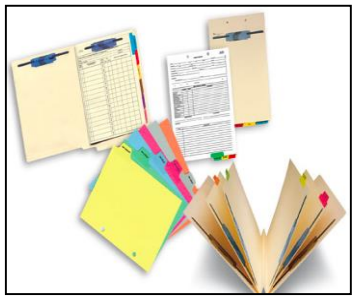
Turning "What Ifs" into Research, Policy, and Patient Information (Case Study - P.I.C.K)

Parents of Infants and Children
With Kernicterus

Researchers
Vinod Bhutani and Lois Johnson

P.I.C.K. Partnerships with Researchers: Developing the Evidence

Registries:
Patient donated data



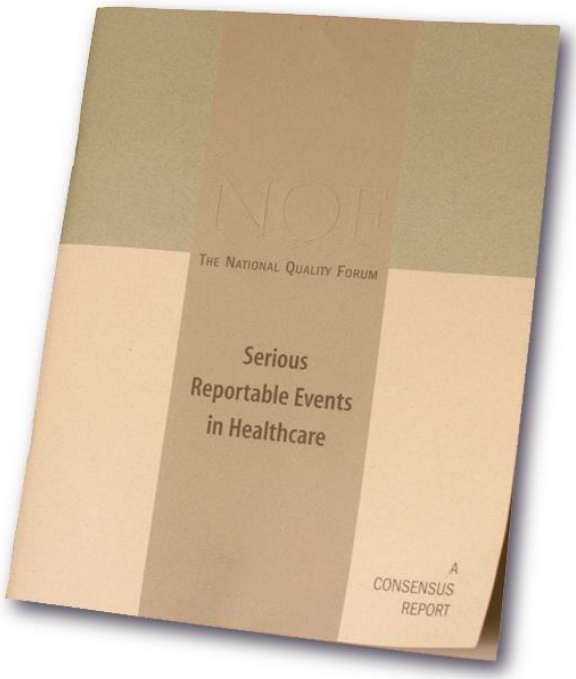
Focus Groups:
HRSA funded

Comparative Research:
HCA donated
Data sets of 250,000 neonates

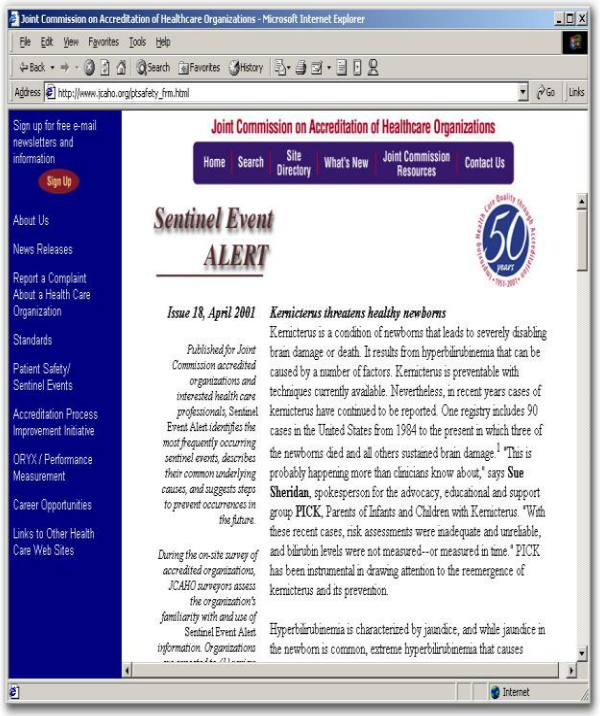
Survey:
CDC funded

P.I.C.K. Partnerships with Policy Makers

The National Quality Forum



The Joint Commission



Patient and Family Engagement with AAP Guideline Developers

"In addition to clarifying certain items in the 2004 ***AAP guideline, we recommend universal predischarge bilirubin screening using total serum bilirubin (TSB) or transcutaneous bilirubin (TcB) measurements"*** *(2009)*

P.I.C.K. Partnerships with US Government Department of Health and Human Services (HHS)

National Parent Education Campaign

Case Study #2 - Pat Sheridan:
Failure to communicate a malignant pathology

THE NATION'S NEWSPAPER

USA TODAY

NO. 1 IN THE USA . . . FIRST IN DAILY READERS

Test delayed: Pat Sheridan sued a Boise hospital and pediatrician, saying son Cal wasn't given a blood test soon enough after birth to detect dangerously high levels of bilirubin. Cal, now 5, has brain damage.

Porous safety net allows lethal medical mistakes

Care has failed to keep up with technological advances

By Robert Davis and Julie Appleby
USA TODAY

An overworked nurse infuses the wrong type of blood into a patient. An experienced pharmacist puts the wrong drug in a child's medicine bottle. A less experienced surgeon blows a heart procedure that is performed more frequently, and flawlessly, down the street.

All the patients die, victims of medical errors. Up to 98,000 such deaths a year — perhaps the nation's most disturbing health care statistic — have health officials scrambling to find fixes. They are spurred by an Institute of Medicine report last November that named errors made by doctors, nurses and hospital workers the USA's eighth-leading killer.

What they have discovered are glaring problems in the health care system, many of which are expected to be at the heart of a new institute report in the next few months.

Among them:

► Too many modern drugs and treatments for doctors to keep in mind as they rush from patient to patient.

► Nurses taking on more work as pharmacies and other hospital departments close early or reduce their staffs to save money.

► A shift toward performing more surgeries in less regulated facilities outside hospitals, such as doctors' offices and clinics, putting patients at greater risk.

► In perhaps the most worrisome development, a slowness by the medical community to embrace technology that could help doctors avoid errors. Not only does the situation create more risk for patients, but it has slowed progress. The federal government has declined to approve some drugs, for example, because it can't trust doctors to remember their complexities.

"Medicine, the way it's practiced in the United States today, can be pretty unsafe," says Andrew Wiesenthal, a Permanente Federation doctor who is overseeing the development of a computer system to help Kaiser Permanente practice safer medicine.

Improvements must be made, he says. "There is a moral imperative about it."

He and others are following the technological success of the Veterans' Affairs hospital in Washington, D.C., where physicians use a $365,000 computer system that scans bar codes on patient bracelets and medicines.

If a doctor is about to make a mistake,

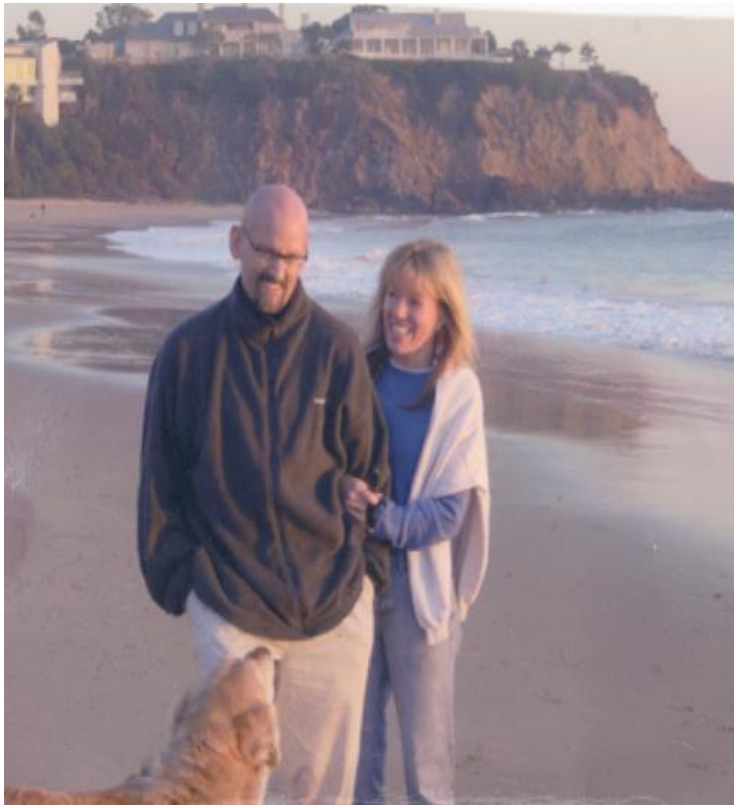
Please see COVER STORY next page ►

Special Report

To err can be deadly

► Sharing data could save lives, Story, 1B

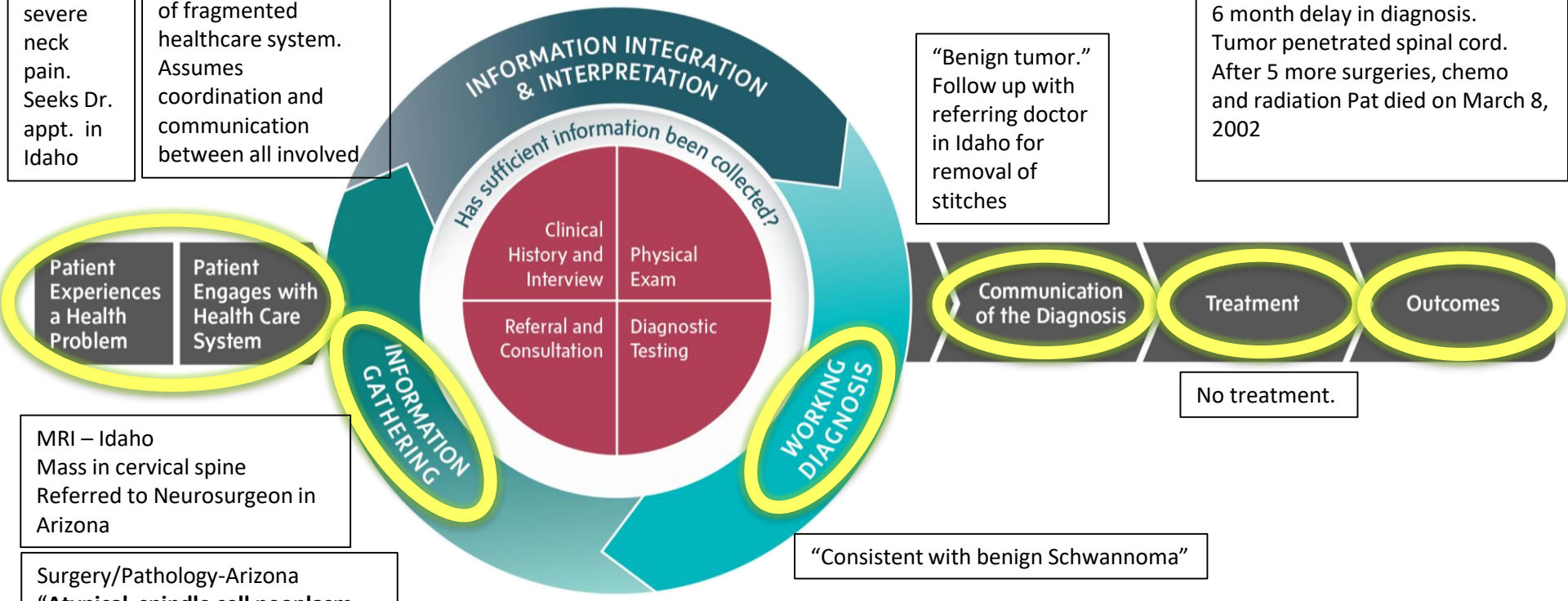
► Talk live at 1 p.m. ET today at talk.usatoday.com



Pat's Diagnostic Journey

Pat has severe neck pain. Seeks Dr. appt. in Idaho

Pat and Sue unaware of fragmented healthcare system. Assumes coordination and communication between all involved



"Benign tumor." Follow up with referring doctor in Idaho for removal of stitches

6 month delay in diagnosis. Tumor penetrated spinal cord. After 5 more surgeries, chemo and radiation Pat died on March 8, 2002

No treatment.

MRI – Idaho
Mass in cervical spine
Referred to Neurosurgeon in Arizona

"Consistent with benign Schwannoma"

Surgery/Pathology-Arizona
"**Atypical spindle cell neoplasm**
Final diagnosis pending"

Final Pathology (23 days later):
Malignant spindle cell neoplasm
Failed to get communicated to Neurosurgeon, referring doctor or Pat and Sue

SOURCE: National Academies of Sciences, Engineering, and Medicine. 2015. *Improving Diagnosis in Health Care*. Washington, DC: The National Academies Press.

The Work System
Factors contributing to Pat's diagnostic error

- Policies and procedures
- Support from central function
- Training and education
- Scheduling and bed management
- Lines of responsibility
- Staff workload
- Supervision and leadership
- Management of staff and staffing lev
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“What ifs” – Communication of Diagnosis

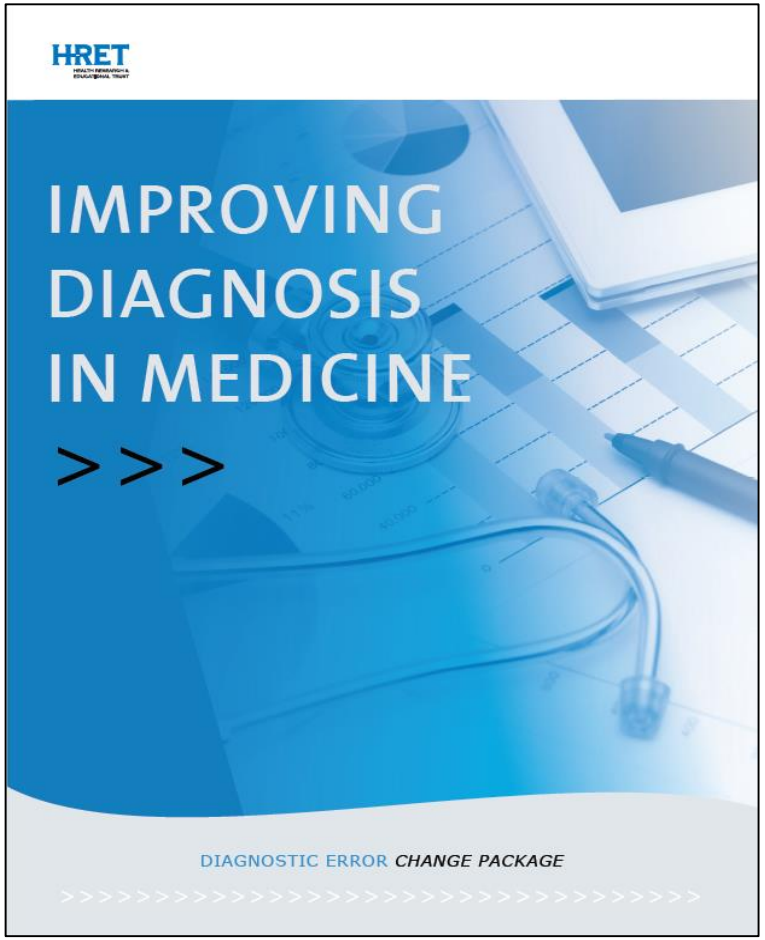
- The pathologist had been part of the “diagnostic team” and played a central role in the diagnostic process and had 2 way communication with the treating clinicians? (Remove the “wall” separating pathologists from treating clinicians)

- The referring physician and I had access to electronic health records (EHRs), including real time clinical notes and diagnostic testing results, to enable us to participate in the diagnostic process and review the health records for accuracy?

“What If”

- Patients and family members were part of the diagnostic team?
- Patients and family members were embedded in the infrastructure of your organization as partners in governance, policy and diagnostic improvement efforts?

Health Research & Educational Trust (HRET) Change Package to Improve Diagnosis in Medicine



http://www.hret-hiin.org/topics/diagnostic_error.shtml

Driver Diagram (v. 2.0)

AIM	PRIMARY DRIVERS	SECONDARY DRIVERS
IMPROVE DIAGNOSIS TO REDUCE HARM	Effective Teamwork	Diagnostic teams include diverse health care disciplines and patients and families
		Diagnostic teams model PFE and culture of safety principles and practices
	Reliable Diagnostic Process	Organizational structures optimized for diagnostic safety
		Clinical operations and information flow effectiveness
		Accessible specialty expertise
	Engaged Patients and Family Members (PFE)	Patient and family members on diagnostic team
		Patient and family partnership in diagnosis improvement, Governance, policy, and in error reporting and follow-up
	Optimized Cognitive Performance	Effective clinical decision support
		Clinical reasoning abilities
		Reflective practice
	Robust Learning Systems	Diagnostic error identification
		Diagnostic performance feedback
		Continuous learning about diagnosis

Driver Diagram (v. 2.0)

AIM	PRIMARY DRIVERS	SECONDARY DRIVERS
HARM	Effective Teamwork	Diagnostic teams include diverse health care disciplines and patients and families
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IMPROVE		Clinical reasoning abilities
		Reflective practice
	Robust Learning Systems	Diagnostic error identification
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		Continuous learning about diagnosis

The Five PFE Strategies from CMS Partnership for Patients

HRET Change Package to Improve Diagnosis in Medicine

- Utilize preadmission planning checklists
- Shift change huddles and bedside reporting with patients/families
- Assign a designated PFE leader
- Include a PFAC or engage patient/family representatives on hospital committees
- Provide patient representation on Board of Directors

Patient and Family Engagement Change Ideas
HRET Change Package to Improve Diagnosis in Medicine

- Create opportunities for patients and family members to use tools and learn about and participate in the diagnostic process (SIDM Tool Kit, preadmission checklist, shared decision making, teach back, patient activation strategies [PAM], discharge planning)
- Provide patient and family member access to their electronic health records (EHRs), including clinical notes and test results, to facilitate patient review of health records for accuracy
- Develop processes and systems in which patients and their families can share feedback and concerns about diagnostic errors and near misses

Patient and Family Engagement Change Ideas

HRET Change Package to Improve Diagnosis in Medicine

- Provide orientation/training regarding diagnostic safety and quality to support patient and family participation in governance (PFACs, Practice Improvement Teams, Board Representatives, etc.)
- Provide understandable discharge information informing patients of serious symptoms to report, to whom to report it and how to escalate
- Develop organizational tools to assess and measure the patient and family member's understanding of their diagnosis
- Develop a rapid response system that patients can activate when a serious change in the patient's medical condition occurs (Code Help)

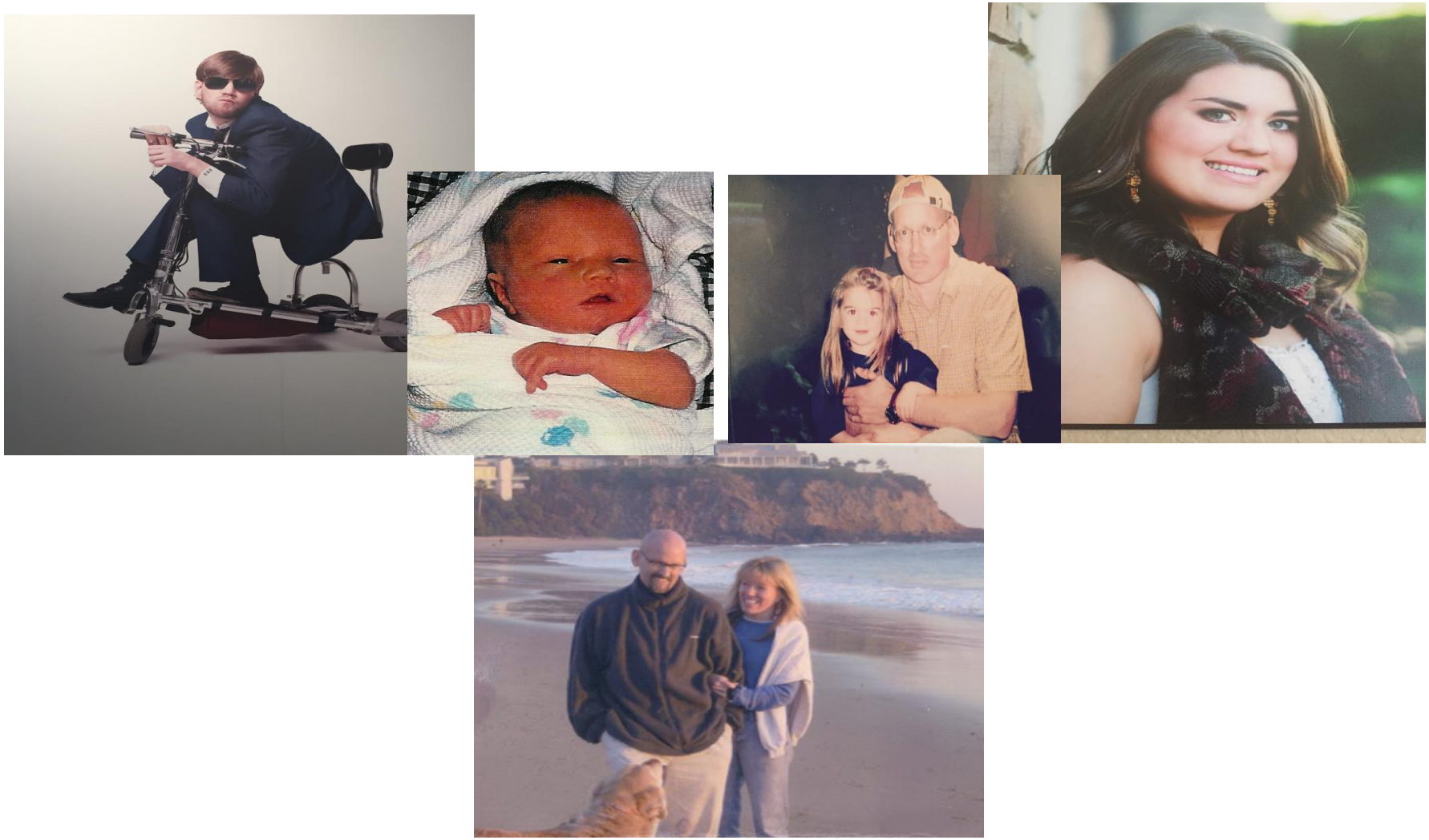
Role of Clinicians in Improving Diagnosis

- Invite patients to participate in the diagnostic process
- Help patients and families have full access to as much information as they want (practice guidelines, websites, unfettered access to the medical records and real time test results)
- Be honest about risk
- Encourage patients to track or journal symptoms
- Instruct patients how to identify and report concerning symptoms, to whom, by when and how to escalate if no action
- Talk about uncertainty – Its OK

Role of Clinicians in Improving Diagnosis

- Discuss diagnostic options - the benefits and risks
- Explain diagnosis in understandable language and confirm patient's understanding of their diagnosis and actions to take
- Persist when diagnosis is difficult – maintain curiosity
- Resist biases – it harms
- Be humble
- Encourage patients to seek a second opinion
- Listen, listen, listen – only patients know what "normal" is for them and are the experts in their own bodies

Why Patient Engagement is Important in Preventing Diagnostic Errors



SOCIETY to IMPROVE DIAGNOSIS in MEDICINE

What if: