Medical information, flow and building "rapid learning" cancer knowledge centers

Craig Nichols, MD

Visiting Professor British Columbia Cancer Agency
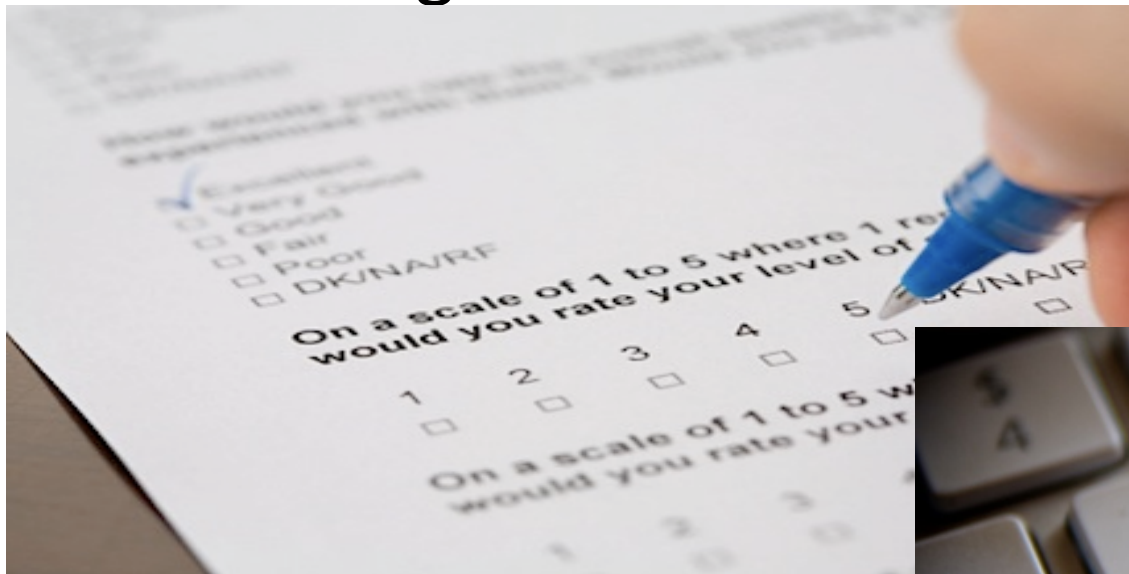
Director-Testicular Cancer Consortium

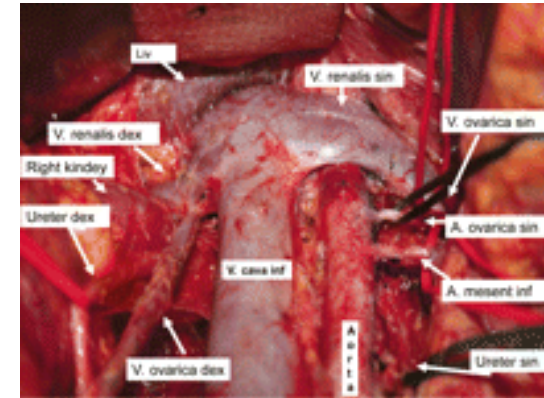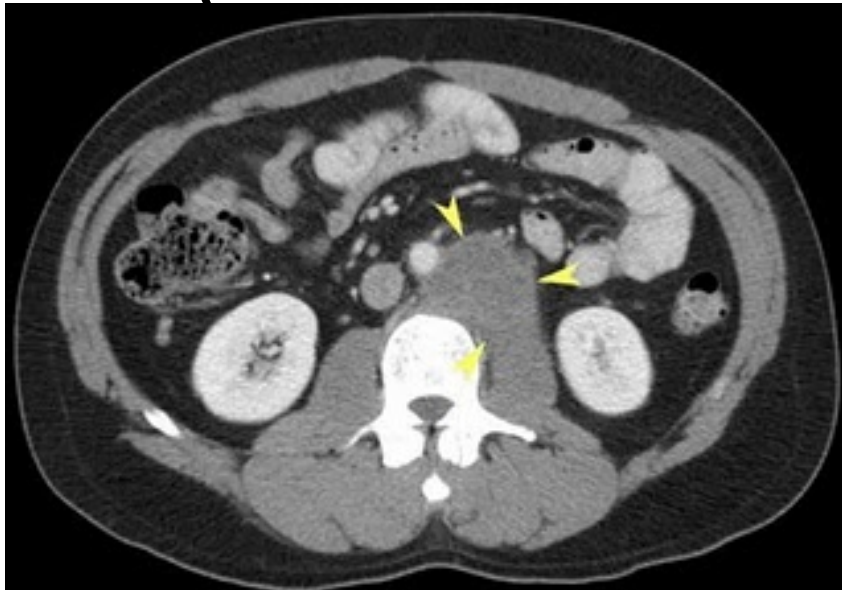LIVE**STRONG**-Health Information Management Interface

Why is medical information different?

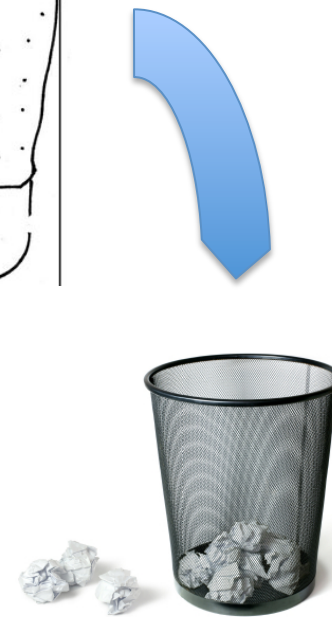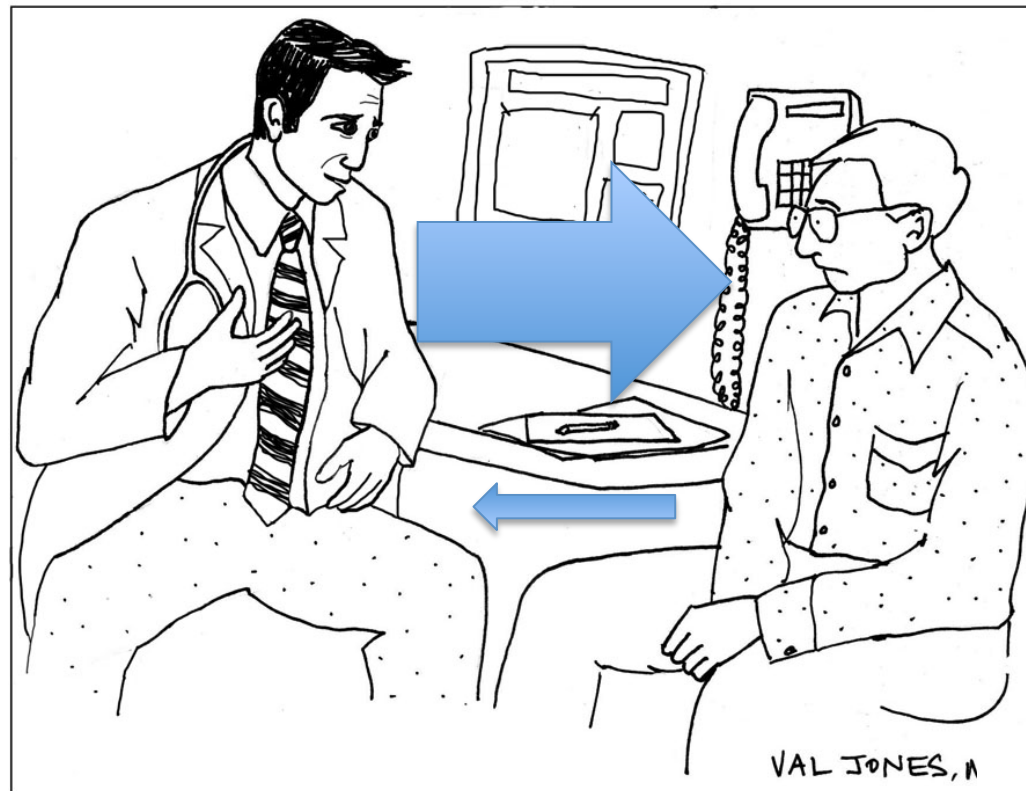# Most information is cheap to obtain

Obtaining consumer information.

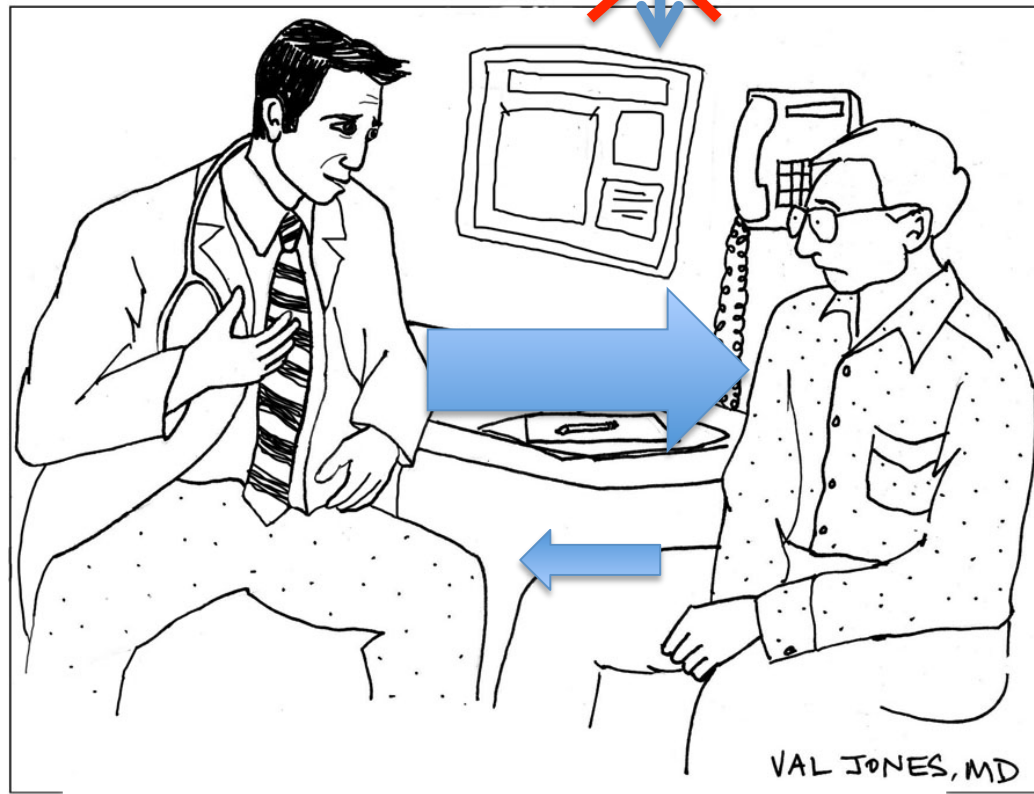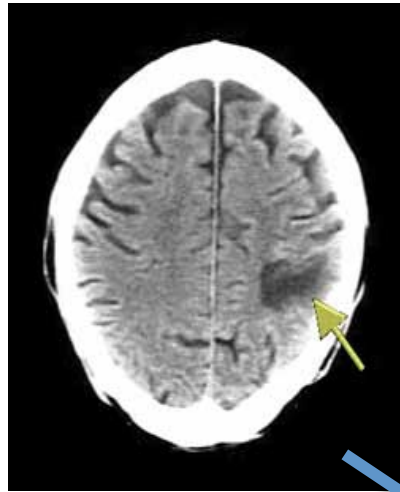# Medical information is uniquely costly (and occasionally fatal) to obtain

What is the current flow of this information that is obtained at such high cost?

Current medical information cycle

Current medical information cycle

VAL JONES, MD
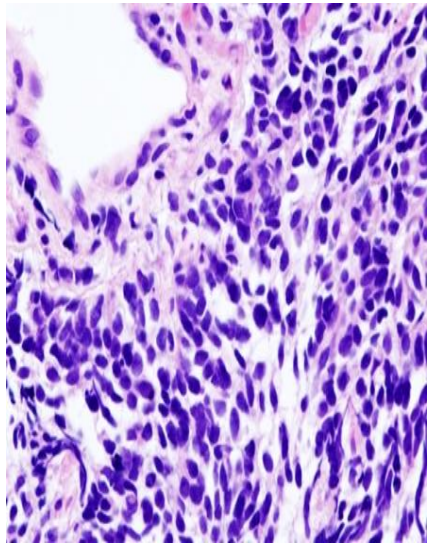
Hub and No Spoke Model
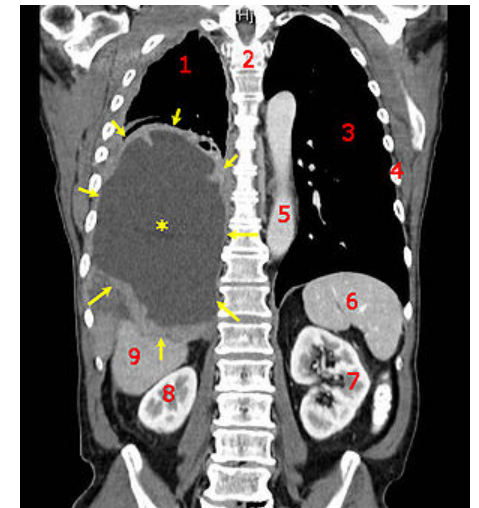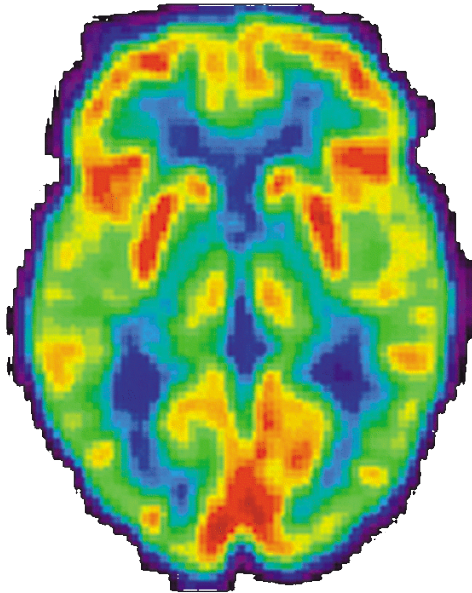
Knowledge centers can have profound favorable effects on outcomes

Knowledge centers and the Berwick "triple aim"

- **Improved health in patients and populations** (Clinical care within knowledge centers in adolescent and young adult oncology have a consistent 10% improvement in outcomes and improved long term health)

- **Enhanced patient experience** (Knowledge centers inspire patient confidence and have improved patient safety profiles)

- **Reduced per capita cost** (Knowledge centers produce improved outcomes at lower costs 30-50% especially in uncommon diseases)

Why can squirrels with brains the size of a walnut break into any bird feeder devised by big brained humans??

Because squirrels think about it ALL DAY LONG

Why is there a delta between outcomes and costs at knowledge centers and outcomes and costs in community practices?

- **Focus and vast experience**! Knowledge centers think about it ALL DAY LONG

- **Consistent and safe delivery of standard of care**

- Rarely are these improved results a reflection of a "technology advantage" at knowledge centers

Challenges in medicine

Discover → **Develop** → **Deliver**

Translational Blocks

Discover ➡ **Develop** ➡ **Deliver**

T1 ⬆

- T1 translational block represents the challenge translating laboratory discovers to patient care ("bench to bedside")

Translational Blocks

Discover → **Develop** → **Deliver**

T1   T2
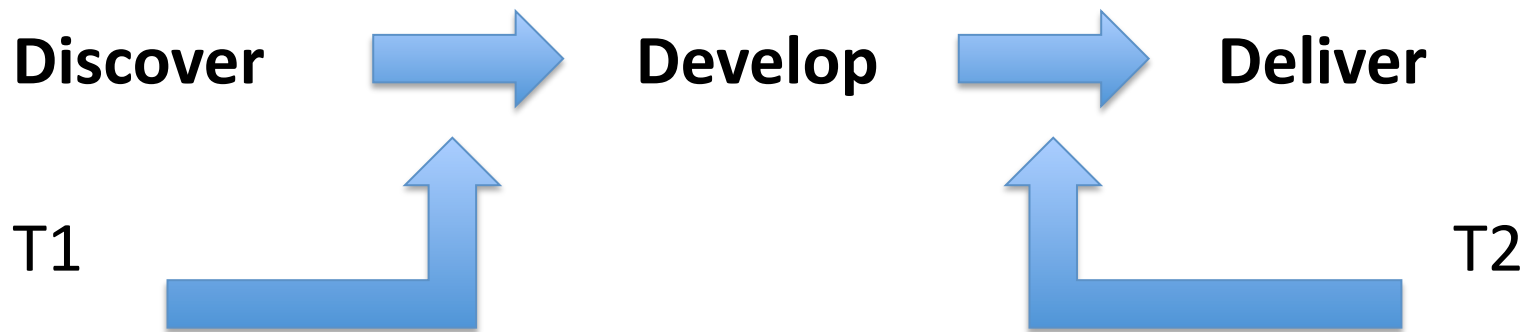
T2 translational blocks represent the challenge of moving developed technologies or care algorithms from knowledge centers to communities

Informatics hypotheses for a T2 solution

#1 High quality, actionable clinical and biological information sets can be aggregated in real time

#2 The real time exchange of comprehensive information sets between individuals and individual providers and the knowledge centers will improve patient outcomes, patient satisfaction and value over broad geographies

What this is about?

- Aligning medical information and knowledge
- Scaling, transferring and leveraging knowledge
- Information conservancy

Old school example

- 25 year old
  - Presented with swollen testicle
  - Biopsy revealed choriocarcinoma
  - Chest and abdominal CT revealed abdominal disease and multiple lung metastases
  - Conventional chemotherapy started in local community hospital

Old school example
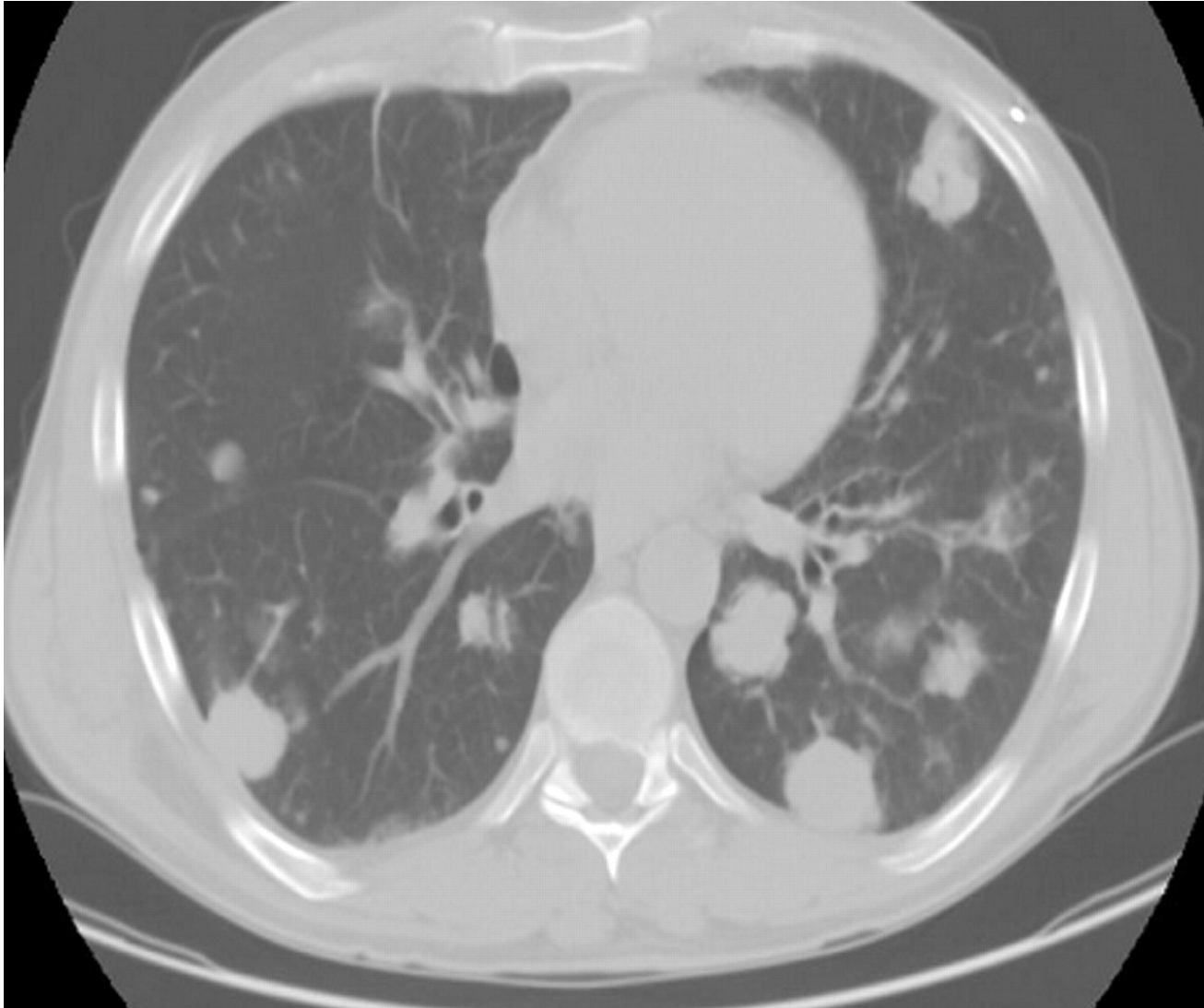
Old school example

- Patient began complaining of headaches
- CT scan subsequently demonstrated multiple brain metastases

Old school example

- Patient seen at world famous cancer institute
    - Received suggestion of very aggressive therapy which would possibly result in cure, but would certainly result in high toxicity including nerve toxicity, impairment of walking and lung function and potentially brain function

Old school example

- Seen at a second "knowledge center"
- Very current knowledge and consideration of patient's personal goals led to a substantial change of therapy that was simpler, more effective and devoid of significant lung, brain or nerve toxicity.
- Patient went on to be cured and currently leads a full productive life.

Then

Now

It's a wonderful life

- What if there were no intense real time application of current knowledge to Lance's information??
  - Higher chance of death
  - Undoubtedly, personal goals of athletic career would have been ended.
  - Likely left with measurable cognitive impairments, lung damage and nerve toxicity
  - Likely would have undergone unnecessary brain radiation, high dose chemotherapy and a large abdominal surgery

Old School Example

- How did this happen?
  - Lance questioned initial recommendations
  - He had access and resources to go anywhere he wanted and he traveled to Indianapolis for his evaluation and treatment
  - He advanced his personal goals along with wanting to be cured
  - We listened to his aspirations and goals
  - We were sitting on a pile of unpublished but defining data that allowed safe change in chemotherapy
  - We had examined our large data sets to refine our management of brain metastases and patients with high HCGs

Information and (lack of) organization

- It is challenging to find, aggregate, enrich and organize information within an institution or business

- It has been extremely challenging to find, aggregate, organize and enrich medical information across the health care landscape because of massive fragmentation, business barriers, distributed and unaffiliated care sites

Pertinent Health Care Reform

- Justice and access
- Requirements to have medical information in electronic formats
- The primacy of clinical decision support
- Patient involvement in medical decision making
- Emphasis on value and evidence-based care
- Emphasis on system wide learning and improvement eg quality assurance
- Emphasis on big collaborative science and large scale scientific infrastructure-eg caBIG

Pertinent changes in Medical/Social Culture

- Health care as a right not as a privilege
- Rise in consumer provided content and perspective in all enterprises
- Patient empowerment and advocacy
- Patient ownership/control of personalized information
- Privacy and portability of medical record
- Emphasis on quality of life
- Cost/Value

"Adjacent Possibilities"

- Marked reduction in ease, speed and cost of real time information transfer (this would not work with dial-up modems) and reduction in cost of information storage
- Rapid penetration of EMRs, digitized imaging and pathology and proliferation of high quality tissue banks
- Ability to push or pull specified data sets from large information systems and ETL technologies
- Large, electronically organized, medical delivery systems-Kaiser, Usoncology/McKesson, VA, active military and whole countries-Canada, Sweden

CALVIN AND HOBBES
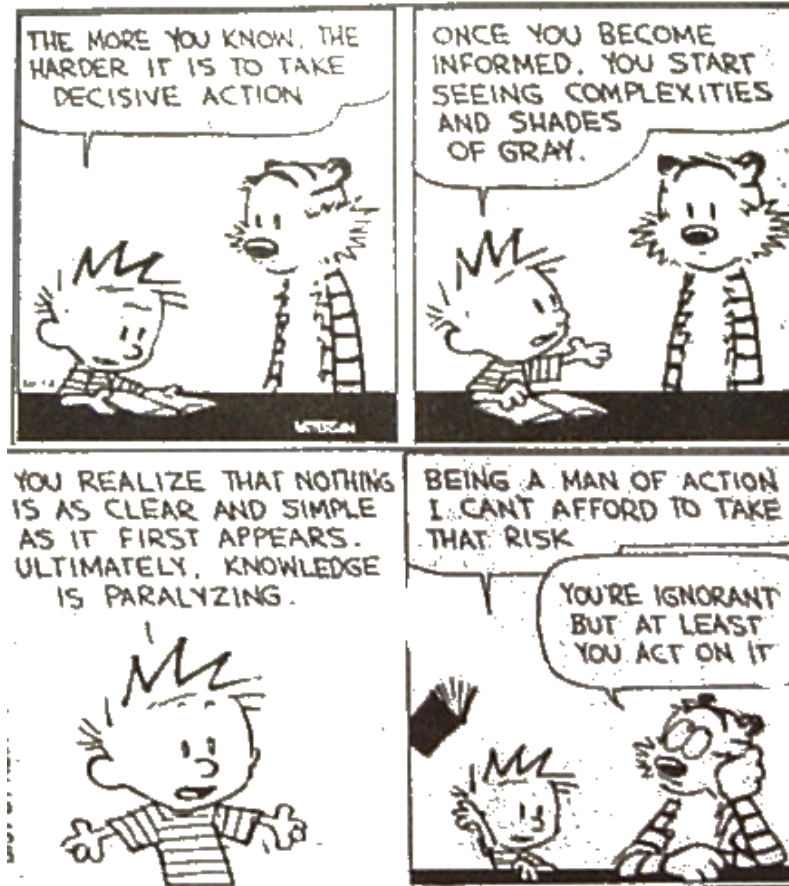
I WANT **YOU**
To Bring Me Nuts
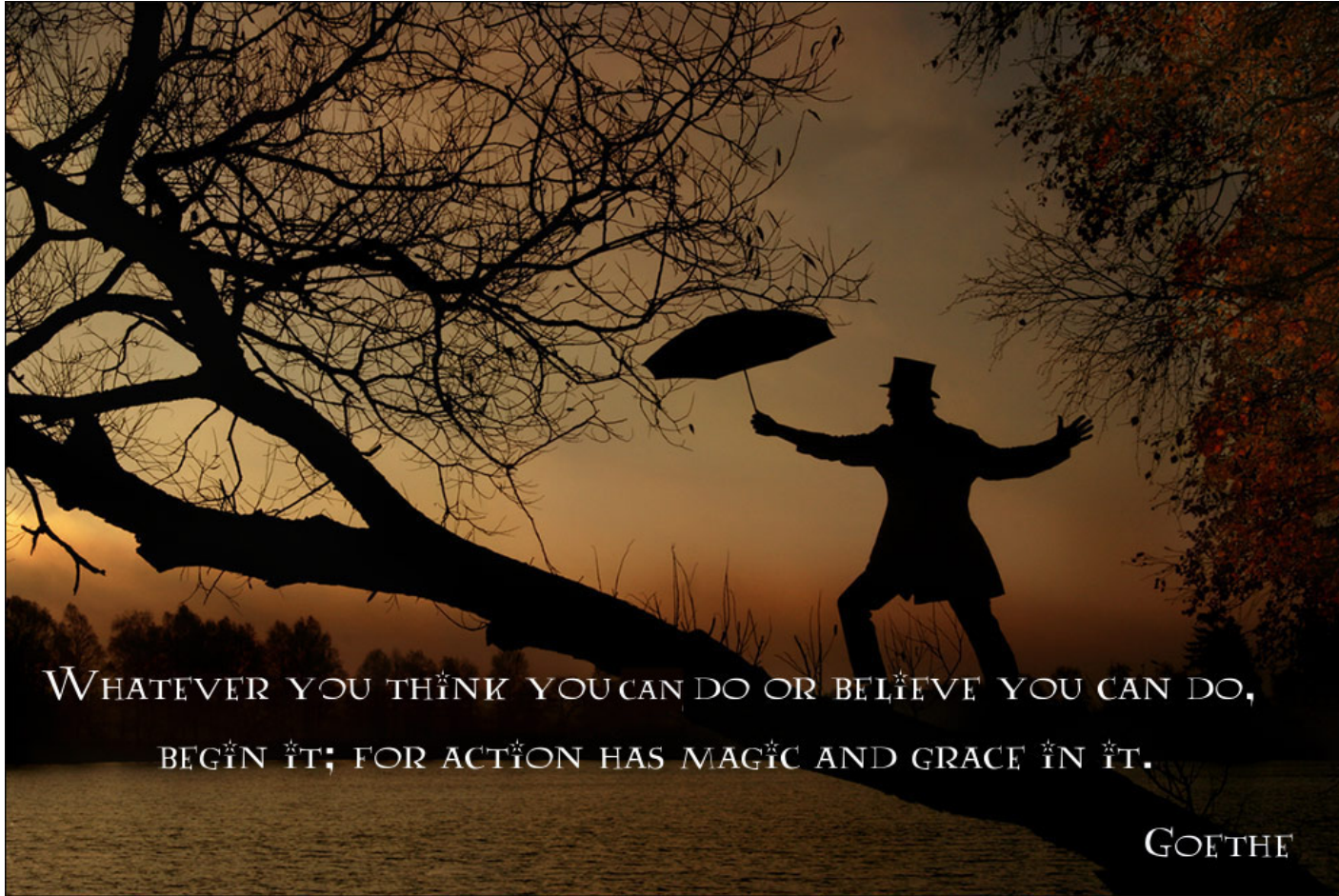
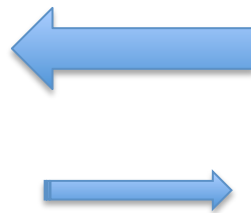WHATEVER YOU THINK YOU CAN DO OR BELIEVE YOU CAN DO,
BEGIN IT; FOR ACTION HAS MAGIC AND GRACE IN IT.

GOETHE

Patient Interface   **Provider/EMR Interface**
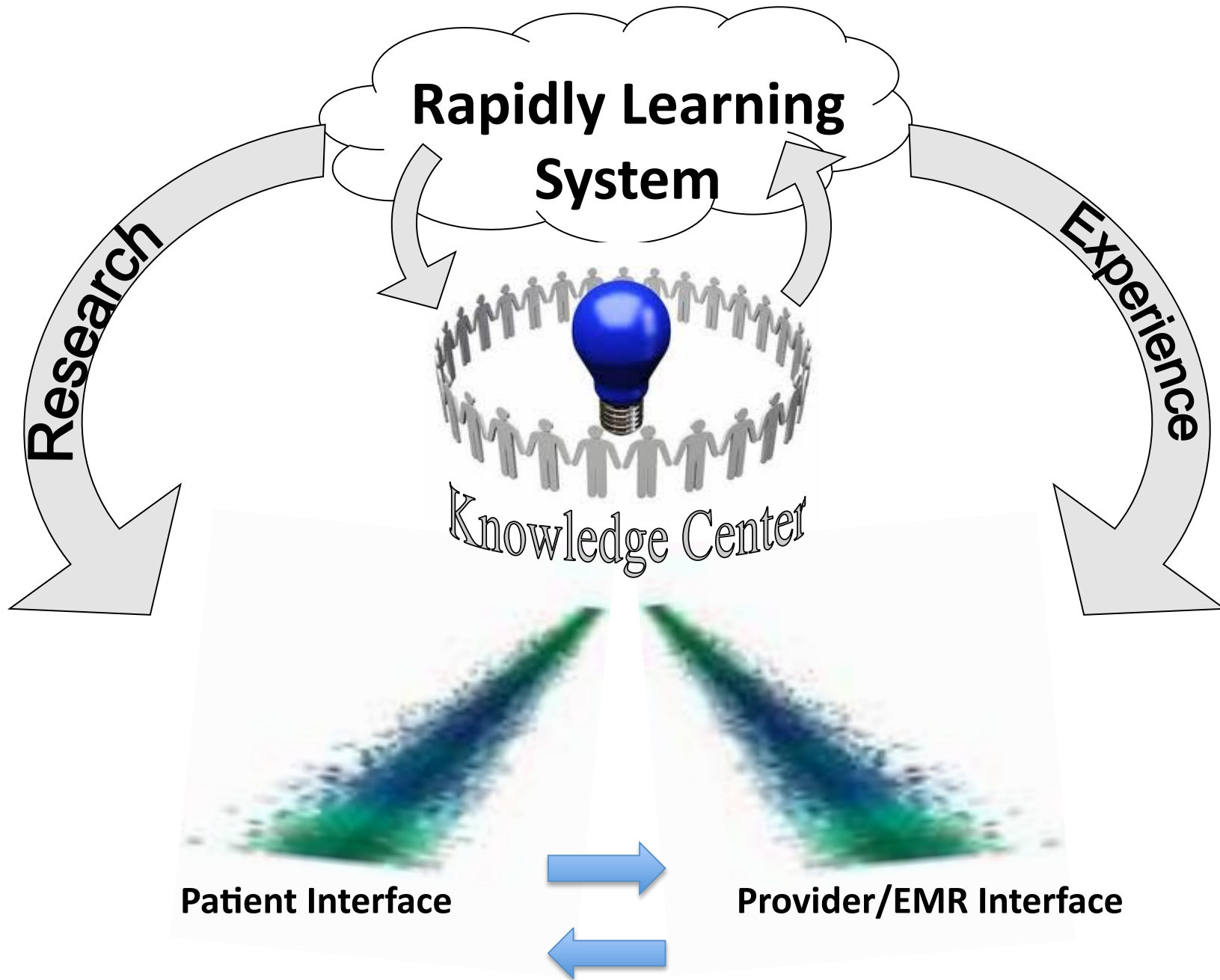
Rapidly Learning System

Research

Experience

Knowledge Center

Patient Interface

Provider/EMR Interface

- **Best Knowledge Available When Needed**
- **High Adoption & Effective Use**
- **Continuous Improvement of Knowledge & CDS Methods**

Pillars of Clinical Decision Support*

Enhanced health care through clinical decision support
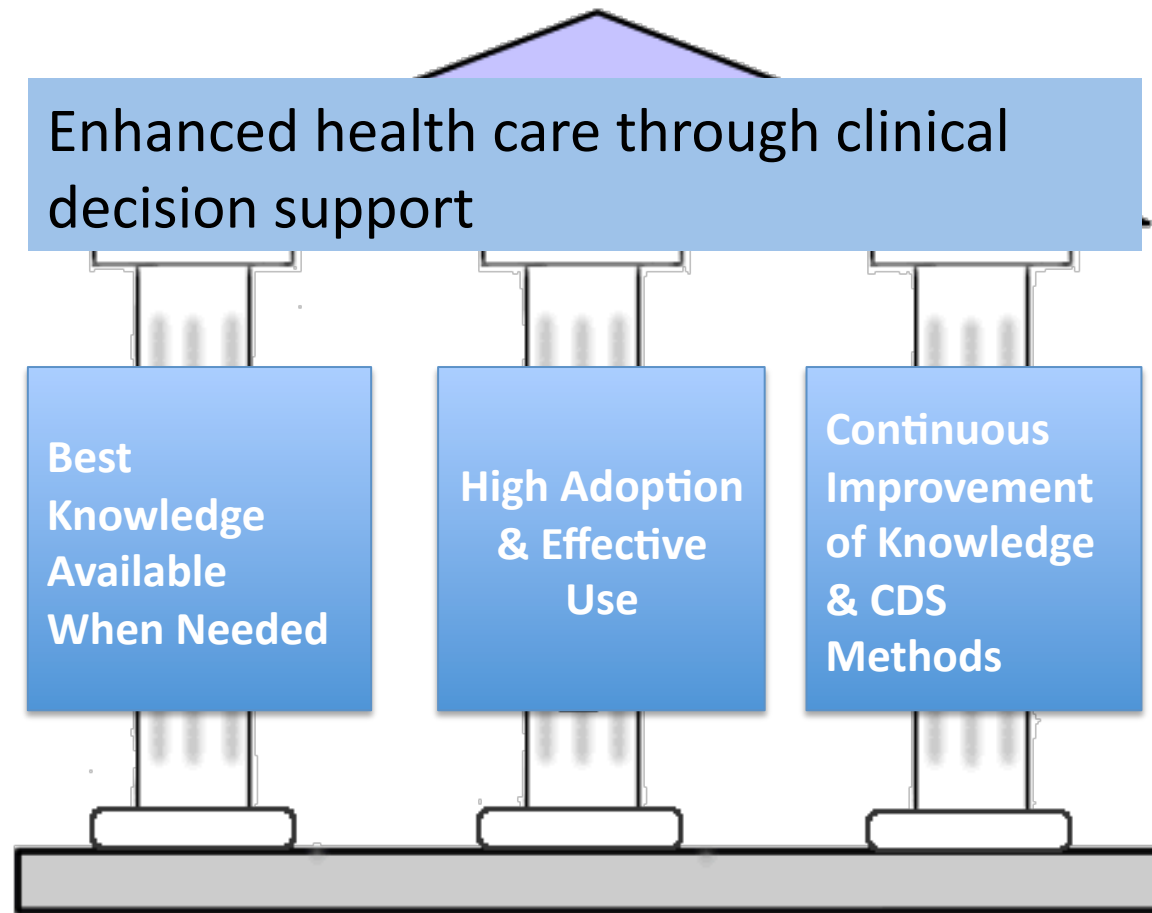
Best Knowledge Available When Needed

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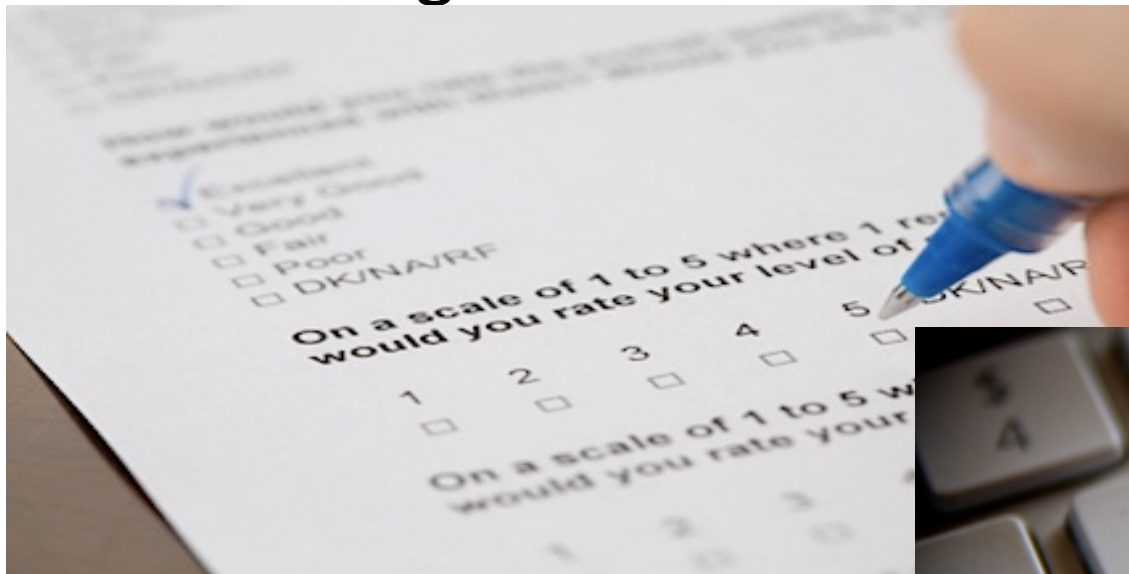* A roadmap for national action on clinical decision support AMIA 2006

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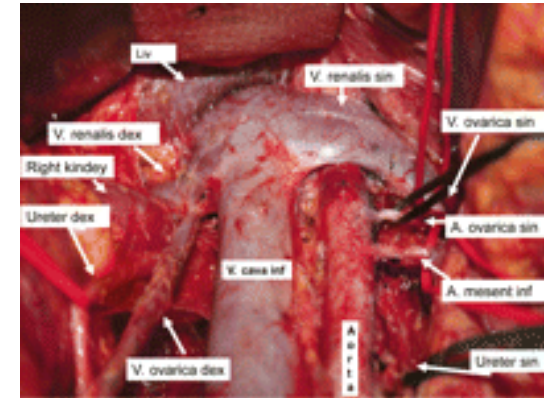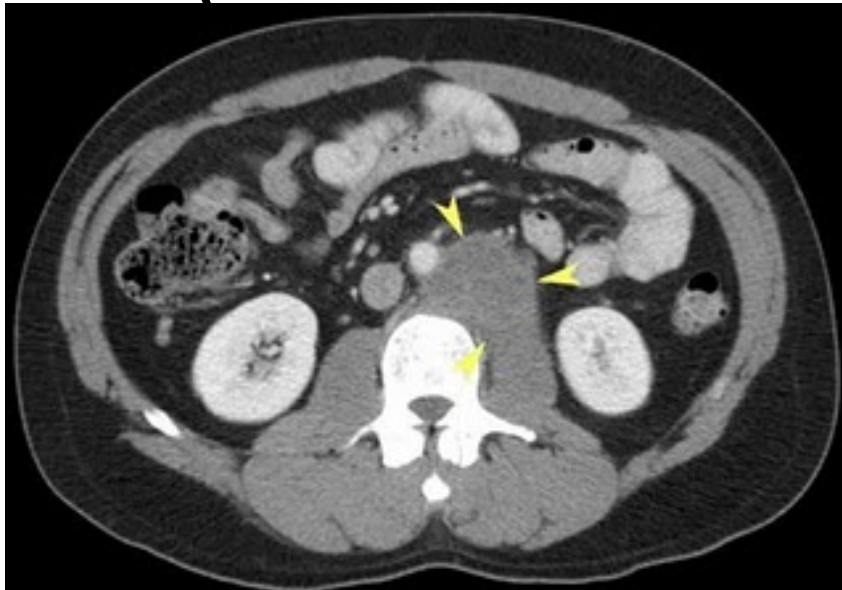
Despite the personal and financial costs of obtaining medical information, it is …..

- Surprisingly discrete and often binary
  - Lab test is normal or abnormal
  - CT shows liver involvement or not
  - Biopsy was positive or not
- Usually in a form that can be copied, electronically shipped and stored
- And <u>almost always</u> is entirely single-use and essentially thrown out

Asymmetric power and information in medicine

Patient Interface

Provider/EMR Interface

Knowledge Center

Patient   Provider/EMR

Knowledge Center

Patient Interface   Provider/EMR Interface

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knowledge processing chain: gathering;
organizing; refining; representing; and
disseminating.

Cancer patients – a marketer's dream

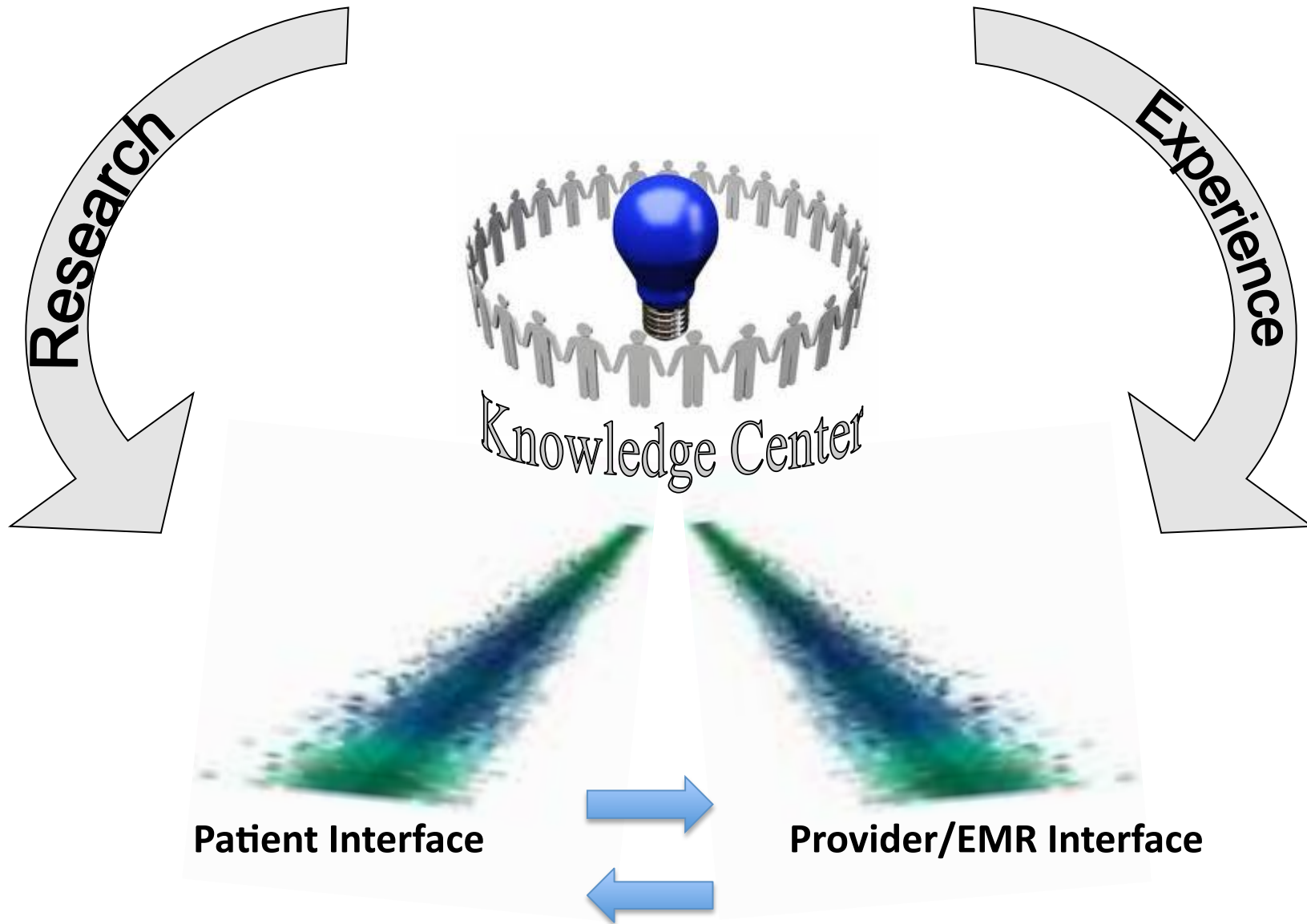| Physician	Patient
"All knowing"	Knows little
Confident	Scared
Reassuring	Panicked
	Fully attentive
Doesn't care about cost	Doesn't care about cost

Knowledge Management Lifecycle
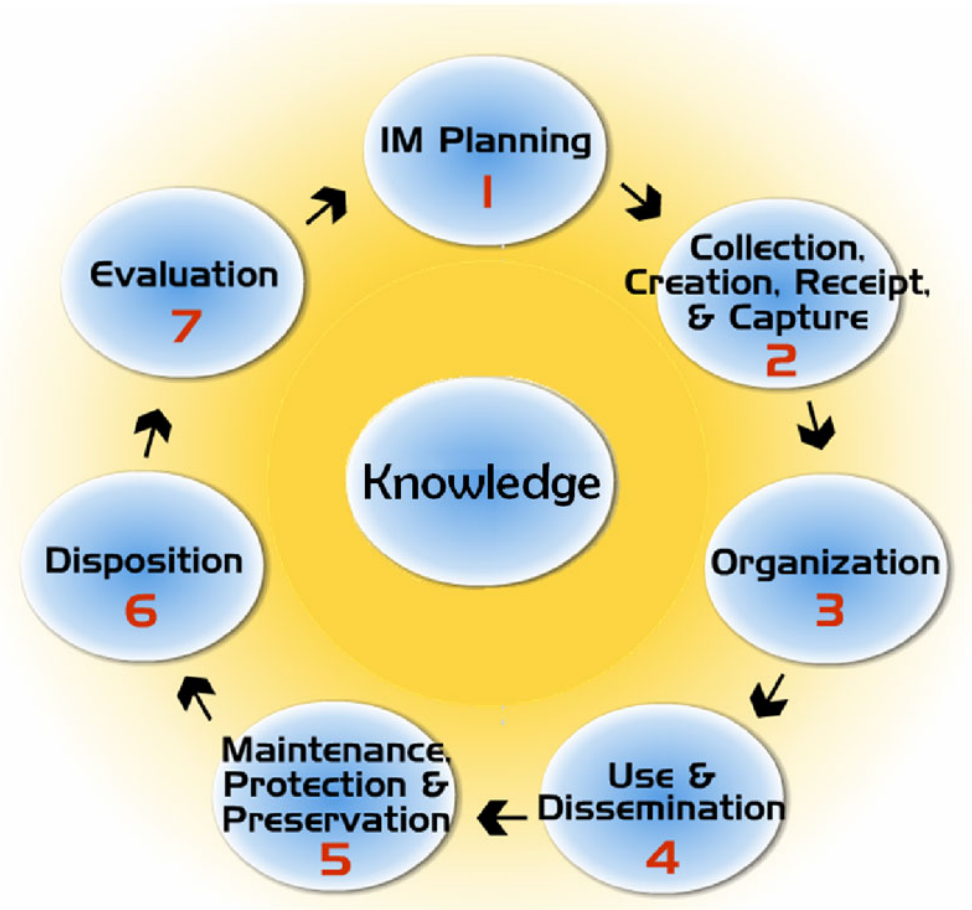
Pilot Proposal

Proposal

- **Use testicular cancer as a model to test…..**

  – The ability to aggregate, in real time, actionable patient and institutional clinical information.

  – The ability to influence positively outcomes and costs by real time information exchange between knowledge centers and patients/community providers.

  – The ability to generate research-quality clinical and biological data sets in a patient-centered environment.

Why a Testicular Cancer Information Exchange as a Pilot Informatics Project?

- **Rare disease**-8500 young men affected in the US annually- rare disease equivalents in young women and children

- **Highly curable**-on average 40 quality life years added by successful management (> 200,000 survivors in the US)

- **Late effects** from disease or treatment are preventable/manageable in most cases

- **Clear cut "center effect"**-10% positive difference in outcomes @ 70-90% cost

- **Model for a curable malignancy**-Testicular cancer has often been the model for moving forward in cancer-rational clinical trial design, survivorship and late-effects and health outcomes research

Beyond Feasibility

If the testicular cancer model proves valuable, the same information exchange model can be applied to other adolescent and young adult cancers (lymphoma, leukemia, sarcoma etc), across borders (Mexico and others) and to large systems (VA, active military, Kaisers, China). Remember, cancer outcomes are determined more often by availability of quality information and knowledge than high end technology.

Current Examples

- St. Jude's international outreach program raised survival of El Salvadorian children with acute lymphoblastic leukemia from 10% to 60% with intense educational efforts on how to make diagnosis simply and reliably and how to use standard and cheap chemotherapies.

- Now utilizes www.cure4kids.org to share online imaging and pathology slides for Central and South America to assist in care decisions.

Testicular Cancer Information Exchange-Centerpieces

- Patient-centered, authoritative, dynamic.

- Individualized, patient-controlled but structured record with patient and provider supplied information.

- Real time expert (human) review of provided data and individualized clinical decision support to guide individual care choices by patient and provider (electronic or via telepresence).

- Aggregation of high quality, patient approved de-identified clinical and biological datasets for research and education.

Patient-Facing

INPUTS	OUTPUTS
Personalized data Fertility concerns Side effects Family history Consent to aggregate data and contact patient	Customized information prescriptions General lay educational materials Detailed side effects profiles Customized "what's new" information Available clinical trials Directory of services in patient's geography
Patient perspective	Customized discussion of treatment options and recommendations
Common Questions	Patient centered social media
Research Questions/proposals	Portable personal cancer health record with structured data
Blogs/Tweets/other social media	Timeline of anticipated clinical events Survivorship plans

Provider-Facing

INPUTS	OUTPUTS
Data sharing agreements for push/pull from EMR, PACS etc	Customized initial and ongoing decision support
Liability waiver	Recommendations for tertiary services (if required)
Structured input on physical exam and history	Customized calendars of events for follow-up
Individual questions to experts	Treatment summary and survivorship plans
	Customized chemotherapy order sets Structured documentation/clinic notes
	Online tumor boards, educational services,
	Alerts, breaking news, new publications

Research Facing

INPUTS	OUTPUTS
Structured annotation	Mature clinical data sets for outcomes and late effects research
Common Medical Language	Contact information for surveys, notifications, late effects information
Natural Language Processing	Clinically annotated biospecimens
Data warehouse	Patterns of care and guideline adherence
Biobanks Biobank SOPs	Research forum
Patient advocacy	
Patient consent and governance	
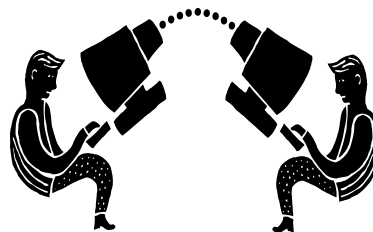
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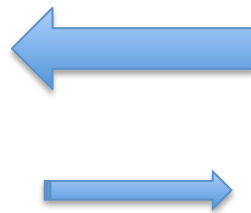
Patient Interface   **Provider/EMR Interface**

Knowledge Center

Patient   Provider/EMR

Knowledge Center

Patient Interface   Provider/EMR Interface

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