Medical information, flow and building “rapid learning” cancer knowledge centers

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LIVESTRONG-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

Doctor, I want to choose how I’m treated

Hmm. You’re not just ill — you’re deluded
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

- T1 translational block represents the challenge translating laboratory discoveries to patient care (“bench to bedside”)
Translational Blocks

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

THE MORE YOU KNOW, THE HARDER IT IS TO TAKE DECISIVE ACTION.

ONCE YOU BECOME INFORMED, YOU START SEEING COMPLEXITIES AND SHADES OF GRAY.

YOU REALIZE THAT NOTHING IS AS CLEAR AND SIMPLE AS IT FIRST APPEARS. ULTIMATELY, KNOWLEDGE IS PARALYZING.

BEING A MAN OF ACTION I CAN'T AFFORD TO TAKE THAT RISK.

YOU'RE IGNORANT BUT AT LEAST YOU ACT ON IT.
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
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

High Adoption & Effective Use

Continuous Improvement of Knowledge & CDS Methods

* A roadmap for national action on clinical decision support AMIA 2006
Most information is cheap to obtain

Obtaining consumer information.
Medical information is uniquely costly (and occasionally fatal) to obtain.
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 almost always is entirely single-use and essentially thrown out
Asymmetric power and information in medicine
Knowledge Center

Patient Interface → Provider/EMR Interface
knowledge processing chain: gathering; organizing; refining; representing; and disseminating.
Cancer patients – a marketer’s dream

<table>
<thead>
<tr>
<th>Physician</th>
<th>Patient</th>
</tr>
</thead>
<tbody>
<tr>
<td>“All knowing”</td>
<td>Knows little</td>
</tr>
<tr>
<td>Confident</td>
<td>Scared</td>
</tr>
<tr>
<td>Reassuring</td>
<td>Panicked</td>
</tr>
<tr>
<td>Doesn’t care about cost</td>
<td>Fully attentive</td>
</tr>
<tr>
<td></td>
<td>Doesn’t care about cost</td>
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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

<table>
<thead>
<tr>
<th><strong>INPUTS</strong></th>
<th><strong>OUTPUTS</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Personalized data</td>
<td>Customized information prescriptions</td>
</tr>
<tr>
<td>Fertility concerns</td>
<td>General lay educational materials</td>
</tr>
<tr>
<td>Side effects</td>
<td>Detailed side effects profiles</td>
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<tr>
<td>Family history</td>
<td>Customized “what’s new” information</td>
</tr>
<tr>
<td>Consent to aggregate data and contact patient</td>
<td>Available clinical trials</td>
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<tr>
<td></td>
<td>Directory of services in patient’s geography</td>
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<tr>
<td>Patient perspective</td>
<td>Customized discussion of treatment options and recommendations</td>
</tr>
<tr>
<td>Common Questions</td>
<td>Patient centered social media</td>
</tr>
<tr>
<td>Research Questions/proposals</td>
<td>Portable personal cancer health record with structured data</td>
</tr>
<tr>
<td>Blogs/Tweets/other social media</td>
<td>Timeline of anticipated clinical events</td>
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<tr>
<td></td>
<td>Survivorship plans</td>
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## Provider-Facing

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

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

Patient

Provider/EMR
Knowledge Center

Patient Interface  ↔  Provider/EMR Interface
Patient Interface  \(\rightarrow\)  Provider/EMR Interface

Research  \(\rightarrow\)  Experience
Rapidly Learning System

Knowledge Center

Patient Interface ↔ Provider/EMR Interface