Keeping the Public’s Trust:  
How to Communicate about NHSN Data and HAI Prevention

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Why we all need effective communication strategies

- Public reporting of healthcare-associated infections
- Patient notifications during infection control breaches
- Emerging threats for patient safety
- Preparing your facility staff and chain of command to discuss HAIs
Communication Landscape

- **HAIs generate significant press**
  - Shift to regional or local focus

- **Wide and varied audiences**
  - Need for reaching a broad healthcare team

- **Our science is complex**
  - Topics can be difficult for consumers to grasp

- **Numerous prevention recommendations**
  - No single behavior can prevent all HAI threats

- **Need for strong risk communications**
  - Patients experience variety of feelings: fear, loss of trust, lack of control
State Legislation Has Increased Transparency with Public Reporting of HAIs

- States required to publicly report some healthcare-associated infections

2004

2013
Evolution of Transparency with Patient Notifications

Addicted and exposed
The former surgical tech at the center of a hep-C scare wrote of loving her life. But, more fatefully, she fell for narcotics.

HEPATITIS C INVESTIGATION
HUNDREDS OF PATIENTS FLOCK TO HEALTH DEPARTMENT
IT'S OFFERING FREE TESTING FOR HIV AND HEPATITIS
Factors Influencing Risk Perception

Perceptions of risk are influenced by many factors, not just numerical data

<table>
<thead>
<tr>
<th>More accepted risks:</th>
<th>Less accepted risks:</th>
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<tbody>
<tr>
<td>Those perceived to...</td>
<td>Those perceived to...</td>
</tr>
<tr>
<td>☐ Be voluntary</td>
<td>☐ Be imposed</td>
</tr>
<tr>
<td>☐ Be under an individual’s control</td>
<td>☐ Be controlled by others</td>
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<tr>
<td>☐ Have clear benefits</td>
<td>☐ Have little or no benefit</td>
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<tr>
<td>☐ Be natural</td>
<td>☐ Be manmade</td>
</tr>
<tr>
<td>☐ Be generated by a trusted source</td>
<td>☐ Be generated by an untrusted source</td>
</tr>
<tr>
<td>☐ Be familiar</td>
<td>☐ Be exotic</td>
</tr>
<tr>
<td>☐ Affect adults</td>
<td>☐ Affect children</td>
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Fischhoff et al. 1981
Maintaining and building trust and credibility within your community is critical.

- Risk communication literature identifies 4 factors that determine whether the public will perceive a messenger as trusted and credible:
  1. Empathy and Caring
  2. Honesty and Openness
  3. Dedication and Commitment
  4. Competence and Expertise

5 Principles of Risk Communications

1. **Acknowledge the situation**
   If you don’t acknowledge the situation, people will think you are not aware and then they will start rumors.

2. **Convey empathy**
   Messengers are considered trustworthy when they convey: empathy and caring, honesty and openness, dedication and commitment, and competence and expertise.

3. **Ensure transparency**
   Be honest, frank, and open. Trust and credibility are difficult to obtain; once lost, they are almost impossible to regain.

4. **Do your homework and brief your colleagues**
   Make sure that you know your data and what you are doing to address patient safety. Make sure your facility and higher-ups know this information as well.

5. **Be ready – have a plan**
   Develop a response plan for the three scenarios you are most concerned about.
Enhancing Transparency
Patient notification events -- what to do when things go wrong?

- Patients may feel fear, loss of trust, and lack of control
  - Give patients and their healthcare providers action steps
- Acknowledge uncertainty
  - Honestly admit when information is not known
  - Explain what you are doing to learn more; provide a timeframe
- Acknowledge emotions
  - Patients may be angry by the situation
  - Be empathetic and even apologize
  - Send the message that you are working hard to get the situation under control

Photo from the Denver Post
Example #1: Using Transparency to Build and Retain Trust

“We realize that you turn to our medical facility to get better. This event is intolerable to us as well, and we want to work with you to resolve the situation and ensure your safety and well-being. We are taking steps to ensure that this event never occurs again in our facility.”
Example #2: Using Transparency to Build and Retain Trust

With a mean lung function of 97.4% our outcomes for cystic fibrosis are among the best in the country.

Why?
Because 10 years ago, we thought our CF program was strong, until we compared ourselves to other children’s hospitals and realized just how far behind we were.

Why?
Because our program needed to get better – and only by learning from other CF programs and being transparent with our patients’ families every day could we start building better protocols together.

But, Why?
Because to save a child, we have to keep asking questions like one.
Example #3: Using Transparency to Build and Retain Trust

Hospital A
- Highest Infection Rates
- Reputation Challenges

Hospital B
- Lowest Infection Rates
- Not Well Known

Hospital C
- Mediocre Rates
- Best Reputation
Example #4: Using Transparency to Build and Retain Trust

- Engaging consumers can be an opportunity
  - Educate about prevention efforts
  - Correct misinformation
  - Build trust
  - Instill confidence
Building Trust Within Your Organization

- Ensure your chain of command is aware

- Reassure chain of command that they will be kept in the loop

- Set up regular briefings

- Prevent unwelcome surprises
  - For example: Change in the numbers of patients impacted or surprising infection rates
What you can personally do to earn and keep public trust

- **Always do your homework**
  - Find out what happened and prepare yourself/facility for responding to tough questions
    - Brief individuals up the chain to prevent surprises
    - Assess who else you should communicate with in the state
    - Engage patient advocates in advance
    - Develop a communication strategy

- **Dialogue as much as possible**
  - Communicate in a proactive manner
  - Avoid communication vacuums which can escalate rumors
  - Be transparent wherever possible

- **Messages must address emotional responses**
  - Expect a variety of emotional and practical responses from consumers
  - Empathy, caring, honesty, openness, dedication are key!
Example #5: Be Ready – Have a Plan

- Pick three scenarios that most concern you
  - Public reporting of high HAIs
  - An outbreak
  - Patient notification

- Identify the people you would need to speak with inside/outside your organization

- Work with your communications staff to develop a plan
CDC’s Patient Notification Toolkit
A template for a successful patient notification

- Why a toolkit?
  - The circumstances may vary, but the communications strategies are predictable and consistent
  - You need to work quickly. Easier to start from a template based on best practices

- Who should use the toolkit?
  - State and local health departments
  - Healthcare facilities

- When to use the toolkit?
  - After a health department or healthcare facility has decided to notify patients

Find the toolkit on www.cdc.gov/injectionsafety
# What Patients Expect to See in a Notification Letter

<table>
<thead>
<tr>
<th>What to Include in a Letter</th>
<th>Key Concerns from Patients</th>
<th>Tone of the Letter</th>
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</thead>
<tbody>
<tr>
<td>How/where it happened</td>
<td>What to do next</td>
<td>Factual, clearly stated</td>
</tr>
<tr>
<td>Possible symptoms</td>
<td>Time frame of disease/testing</td>
<td>Apologetic, empathetic</td>
</tr>
<tr>
<td>Corrective action</td>
<td>Who’s paying for what</td>
<td>Personal, urgent</td>
</tr>
<tr>
<td>24 hour contact number</td>
<td>Who’s liable</td>
<td>Soft/neutral</td>
</tr>
<tr>
<td>Something to ensure the right people are contacted</td>
<td>What is the disease and how serious</td>
<td>Accommodating to the potentially infected</td>
</tr>
<tr>
<td>Plan of action/next steps</td>
<td>Want assurance they are contacting the right person</td>
<td>Assuring that things will be taken care of</td>
</tr>
</tbody>
</table>

Schneider et al, *J Patient Saf* 2013:9;8-12
PUTTING IT INTO PRACTICE
Lessons learned from the Outbreak of Fungal Meningitis and Other Infections
**TIMELINE**

May 21, 2012
First lot of contaminated steroid injections produced by NECC

September 18, 2012
First meningitis case reported to TN Dept. of Health

September 25, 2012
Seven more patients identified by TN Dept. of Health all were treated at the same ambulatory surgical center

September 26, 2012
NECC voluntarily recalls three implicated lots of steroid injections
**September 27, 2012**
NC Dept. of Health and Human Services informs CDC of a patient with similar symptoms to those in TN

**October 4, 2012**
CDC activates its Emergency Operations Center. FDA confirms the presence of fungi in unopened vials of NECC steroid injections

**October 6, 2012**
NECC expands its recall to include all products distributed from the Framingham, MA facility

**October 15, 2012**
FDA releases an alert stating the sterility of any injectable drugs produced by NECC are of significant concern

**October 18, 2012**
CDC announces that the environmental mold *Exserohilum rostratum*, has been recovered from unopened vials of steroid injections

**October 19, 2012**
More than 99% of potentially exposed patients have been contacted by local, state, or CDC personnel informing them of their risk
A Tragedy for 14,000 Patients

- Diane Reed – a 56yo primary caretaker of her wheelchair-bound husband; became the 3\textsuperscript{rd} TN death

- George Carey -- 65yo husband of Lillian who lost her life to fungal meningitis. George is still battling symptoms.
Outbreak of Fungal Meningitis and Other Infections

- Significant past experience with patient notifications
- Most patient notifications are around injection safety issues (bloodborne pathogen issues)
- Differences from past experience
  - Geographic spread (23 states received one of the three contaminated lots)
  - Rarity and the severity of the illness
- During patient notifications, clinicians and patients need “action” steps
Communication Strategy: Fungal Meningitis

Patient Outreach

- Ensuring patients had the necessary information
  - Provided names and locations of facilities that received product in a clickable map
  - 2 new websites with daily updates with English and Spanish info
  - Thousands of CDC INFO calls answered
  - Monitored and responded to social media in real-time

- Based patient outreach on previous formative research and experience

99% of patients warned of the need to seek immediate care in less than one month
Communication Strategy: Fungal Meningitis

**Media Outreach**

- Provided media with information to disseminate the message broadly
  - Multiple press conferences
  - Invited press to CDC for tour of EOC and laboratory
  - Provided daily 2pm updates
  - B-roll package and still images
  - Digital Press Kit updated regularly
  - 2 press officers working full-time
  - Provided Spanish-speaking spokesperson
Communication Strategy: Fungal Meningitis

Clinician Outreach

- Enhancing clinician outreach
  - Reached out to 245 professional organizations
  - Provided rapid notification to clinicians
    - 10 Health Alert Network notifications
    - 4 new treatment guidelines, updated regularly
  - Held clinical conference calls
    - 4 COCA calls and two webinars (reaching >5,500 clinicians)
  - Facilitated mechanisms to answer clinical questions directly
  - Enlisted public-private partnerships
CDC Applauded for Communication Efforts

“When a dangerous disease outbreak hits social media, the connected generation trusts some governmental agencies more than others, and Twitter users tend not to panic.”
Mashable.com
October 16, 2012

“[CDC has] done an excellent job in communicating this story to clinicians and patients a like. From the website, to FAQs, to clinician webinars…the CDC has been transparent, clear, direct and timely.”
Reflections On Contemporary Issues In The Fields Of Business Continuity Planning & Emergency Management
October 20, 2012

“When it comes to a public health crisis, the public apparently wants to know what the Centers for Disease Control and Prevention has to say”
Fedblog
October 16, 2012
Building trust takes commitment before the crisis

“The CDC has spent buckets of time, money, personnel and resources on establishing themselves as a credible, plain language, accessible, available source of health information, and now we’re seeing the result of that effort. In a crisis, the public (and the media) are turning to them for updates and the latest news...If we want to be trusted in a crisis, we have to build that trust before the crisis. And there’s no shortcut for doing that.”

The Face of the Matter
October 17, 2012

http://faceofthematter.com/2012/10/17/building-trust-is-an-everyday-job/
Keys to Success

- **Be transparent by demonstrating**
  - Honesty & openness, empathy & caring, dedication & commitment, and competence & expertise
  - Acknowledge uncertainty and patient’s fears

- **Listen and be compassionate in your messaging**
  - Include patient advocates, your audience, in your planning efforts

- **Staying ahead of the communication curve**
  - Communicate often
  - Utilize a traditional and social media strategy

- **Ensure collaboration with key stakeholders**

- **Build trust in *advance* of a crisis**

- **Prepare in advance so you can *ACT FAST!***
Questions?

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