Best Practices in Patient Notification:
What Patients Want to Know When Things Go Wrong

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The findings and conclusions in this presentation are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention
Introduction

- Between 2001 and 2011, identification of unsafe injection practices in healthcare settings prompted 35 separate notification events, in which more than 130,000 people were recommended to seek bloodborne pathogen testing.
- Unsafe injection practices and other lapses in basic infection control are entirely preventable.
- Increased public attention due to media coverage, large scale notifications, and legal proceedings.
- Managing a notification can be daunting.

Outline

- **Focus groups** assessing perceptions and preferences surrounding patient notifications
- **Stakeholder meeting** with partners to elicit best practices in patient notifications
- CDC’s **Patient Notification Toolkit**
Who we asked

- 6 Focus Groups (3 in ATL, 3 in NYC)
- Demographics:
  - Total participants: 53
  - Mean age: 54.9
  - % Female: 49.1

What we learned

- Preferences for patient notification
  - Phone call (not a recording)
  - From a healthcare provider at the facility where the incident occurred

- Information to include in a letter
  - Description of the corrective actions

- Preferred tone of letter
  - Personal and empathetic

### 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>
</tr>
</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>

Stakeholder meeting

- Accreditation Association for Ambulatory Health Care
- Agency for Healthcare Research and Quality
- American Association of Nurse Anesthetists
- American Society for Healthcare Risk Management
- Association for Professionals in Infection Control and Epidemiology
- Association of State Territorial Health Officials
- B & D Consulting
- Becton Dickinson
- Broward General Medical Center
- CDC Foundation
- Centers for Disease Control and Prevention
- Centers for Medicare & Medicaid Services
- Consumers Union
- Council of State Territorial Epidemiologists
- Covidien
- Department of Veterans Affairs
- Emory University
- Food and Drug Administration
- HONOReform
- Hospira
- LA County Department of Public Health
- Lehigh Valley Health Network
- Mother's Against Medical Error
- National Association of County & City Health Officials
- Nebraska Department of Health and Human Services
- Nevada Institute for Children's Research and Policy
- Nevada State Health Division
- Nevada State Medical Association
- New York City Department of Health and Mental Hygiene
- New York State Department of Health
- New Hampshire Patient Voices
- Premier Safety Institute
- Rose Medical Center
- Safe Care Campaign, Inc.
- Southern Nevada Health District
- University at Albany, State University of New York
- University of Nevada, Las Vegas
- Vanderbilt University
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](http://www.cdc.gov/injectionsafety)
Early Decision Points

- Who is going to be in charge of the notification?
  - Patients prefer the notification to come from the healthcare facility

- Can the healthcare provider/facility be impartial in the notification process?

- Does the healthcare facility have the manpower or resources to do the notification?
4 Steps to a Patient Notification

1. Develop patient notification materials
   - Letters to patients and healthcare providers
   - Phone scripts
   - Notifications of testing recommendations

2. Plan for questions from the media and public
   - Prepare for common media questions
   - Spokesperson prep

3. Establish communication resources
   - Set up a call center
   - Questions and answers from previous notifications

4. Develop a release plan to notify patients and stakeholders
   - Follow best practices in patient notifications
Step 1: Develop patient notification materials

- **Option 1: A Letter**
  - Letters provide a consistent message and gives patients’ something on paper
  - Tailor letters based on whether there is known disease transmission
  - Don’t be afraid to provide an apology

- **Option 2: A Phone Call**
  - Callers will need a consistent script and be prepared to answer questions
  - Can be difficult to accomplish in a large-scale notification
  - Patients prefer a phone call (40% vs 27% preferred a letter in CDC focus groups)

- **Option 3: Both a Call and Letter**
  - Preferred by patients during fungal meningitis outbreak
How do you translate this guidance into communication products?

- Develop goals and build key messages around them

- For example:
  - Goal 1: Explain the risk and ease public concern
    “We believe the risk to patients is low.”
    (Don’t try to quantify the risk)
  - Goal 2: Give guidance on how to respond
    “Get tested…” “…contact your healthcare provider.”
  - Goal 3: Convey empathy
    “All of us at [Medical Center Name] understand that this is alarming and may be frightening.”
Step 2: Plan for questions from the media and public

- Media can be very helpful
  - Rapidly convey important health information
  - Particularly helpful in large-scale patient notifications
  - Patients may be difficult to reach; media can spread the word

- Plan for media whether you intend to engage them or not
  - It is possible that patients or healthcare personnel may independently contact media during the investigation/notification
Tips for Working with Media

- Move at a pace that the media and patients impacted will perceive as appropriate
  - Start with information that can be verified
  - Alert the media and the public that more information will come as more becomes available
  - Keep the media engaged even if you don’t have all the answers

- Coordinate with other involved players who may be talking with media and share talking points
  - For example: health department, law enforcement, or licensing body
5 Main Talking Points

1. Explain how the exposure occurred and why it puts a patient at risk

2. Clarify the actions patients need to take if they were exposed

3. Provide a description of the steps of the investigation

4. Provide a timeline for the investigation including communicating patient test results

5. Give details on what is being done to make sure the event doesn’t happen again
Common Questions from Media

Who is in charge?

Who is affected?

How could this have happened?

When did this happen?

Why wasn’t it prevented?

Has it happened in the past?

Is the facility inspected?

What came out in the last inspection?

When did you begin working on this?

Will the healthcare personnel responsible be suspended or lose their license?

What is being done to prevent this from happening again?

Why was there a delay in notifying patients?
Media Resources in CDC’s Patient Notification Toolkit

- **Tips for spokesperson prep**
  - Preparing for a media interview
  - Press conference prep
- **Decision points for hosting a press conference**
- **Collaborating with the media to tell the whole story**
- **Sample press releases**
- **Sample media backgrounders**
Step 3: Establish communication resources

- Patients often want to speak with a knowledgeable person after receiving the letter.
- Depending on the size of the notification, it may be necessary to establish a call center:
  - A call center can manage the flow of information to and from a large number of callers, enabling healthcare facility and health department staff to focus on conducting the investigation.
- Need FAQs for impacted patients and worried well.
Step 4: Develop a release plan to notify patients and stakeholders

- **Send letters early in the week and be aware of holidays**
  - Patients will need several days to understand and process what has happened before they can act
  - It is best if patients can make necessary appointments for testing within a day or two of receiving a letter
  - Your staff or call center should be in place to respond to inquiries.

- **Think about the media and timing of the press release**
  - It may be best to alert media after letters have been sent to patients.

- **Prepare for a flood of calls**

- **Don’t delay!**
Don’t forget key stakeholders!

- **Identify the core stakeholders**
  - For example: individual medical licensing board, governor’s office, local political figures, professional organizations, patient advocates, health insurance providers

- **Anticipate and assess the incident from the stakeholder perspective**

- **Be prepared to respond to their questions**

- **Provide timely, accurate information**

- **Focus on common concerns and reactions that will have to be addressed**

- **Give stakeholders periodic updates including talking points, and resources for their use**
Implications

- Patients don’t expect to be put at risk for an infectious disease when seeking treatment for something else
- Notification process itself is not without risk of causing harm to patients
- Heightened need and responsibility to conduct a patient notification that effectively and accurately communicates the risk to patients and what actions they should take
Thank You

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Access the toolkit:
www.cdc.gov/injectionsafety