

Developing the National Public Health Surveillance and Biosurveillance (NPHSB) Registry for Human Health: Lessons Learned and Implications for Public Health Informatics

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What is the National Public Health Surveillance and Biosurveillance Registry for Human Health?

We must know who is doing what before we can facilitate information exchange...

The Registry is

- An electronic catalog of CDC's surveillance activities.
- A database which holds background information about these activities.
- Currently, there are 285 activities in the Registry.

The Registry is not

- A surveillance system.
- A database that contains surveillance data.



Why was the NPHSB Registry Created?

Having up-to-date access to surveillance related information is critical to building collaboration and enhancing response...

- Part of a nationwide approach to integrating biosurveillance and enhancing the United States' ability to detect and respond to health threats
- Lack of a current and accurate view of the state of our national biosurveillance capability:
 - Across federal sectors;
 - Within State, local, and territorial jurisdictions; the private sector and
 - At interfaces between the U.S. and the global surveillance network.
- Lack of a common and accessible repository of information on human health biosurveillance activities that is:
 - Accurate;
 - Up-to-date;
 - Easy to manipulate; and
 - Easy to query.

Benefits of NPHSB Registry

Information sharing can help facilitate important public health planning and response efforts...

- **BROAD INFORMATION CAPTURE** – NPHSB Registry captures information about existing human health systems across human, animal, environment, and plant domains.
- **SURVEILLANCE-CENTRIC** – The NPHSB Registry is designed around the needs of surveillance experts; Subject Matter Experts (SMEs) can quickly find information they need and readily exchange knowledge, experience, and interests with colleagues.
- **ACCESSIBLE** - Information is easy to access; information about CDC's surveillance-related activities will no longer be scattered or buried in nested program websites. It makes critical information about our nation's human health surveillance capability more accessible to decision makers.
- **SEARCHABLE** – Information is easy to query; an electronic format will allow data captured in the NPHSB Registry to be queried by user-defined parameters and for information to be provided in customized reports.

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Approaches Used and Lessons Learned in a Number of Domains Including ...

Project Management

Use of strong Project Management principles is critical to project success ...

- **Begin the project with a charter signed** by the sponsor.
- **Conduct a systematic analysis of the "as is" process**, identify gaps and formulate a transition plan for the "to be" state.
- **Maintain leadership buy-in** and continue to educate them about the project. Closely manage leadership expectations.
- Train multi-functional teams to ensure adequate skill sets.
- **Leverage common resources** to improve operational efficiency.

Survey Development

Intended use of the information should drive formulation of the survey questions...

- **Need a systematic method to develop the Survey**, which includes:
 - **Engaging** a multi-disciplinary team of **Subject Matter Experts**.
 - **Following effective facilitation processes** to manage requirements from a diverse group of experts.
 - Writing survey questions and response options based on how the information will be used.
 - **Following standard survey design methodology** and practices.
 - **Focus testing the questions** to make sure that the survey has adequate reliability and validity.

Stakeholder Engagement

Keep stakeholders informed and involved throughout the project...

- Provide **multiple avenues to engage with stakeholders** (e.g. Open house, In person meeting and Net Meeting).
- **Use a personalized approach** when engaging with stakeholders.
- **Gain leadership buy in** across the agency in the "value added" of the project and obtain a mandate for stakeholder participation.
- **Prepare guidance** to ensure that stakeholders respond to questions consistently.

Technology

Do not allow the technology to drive your requirements...

- **Conduct a comprehensive alternatives analysis** to ensure that an integrated IT solution is selected to support data collection, analysis and reporting.
- **Conduct a "proof of concept"** to systematically test shortlisted options prior to selection.
- **Engage a panel of informatics experts** to validate the alternatives analysis, the short-listed options and the final selection.
- **Develop a thorough systems architecture design** aligned to the Organizational IT strategy and Program's long term objectives.
- **Ensure that project requirements drive the technology** and not vice versa.
- **Use shared technological solutions** to the extent possible to leverage common resources.

Data Collection, Analysis and Reporting

Integrate and introduce established policies and practices into the data management lifecycle to ensure data quality ...

- **Engage extensively with stakeholders**
 - Create accurate and relevant content for the data collection instrument.
- **Develop comprehensive "help" resources**
 - Provide definitions of key terms through user friendly display options.
- **Develop a data release policy**
 - Reassure registrants (SMEs) that their data will be managed and used responsibly.
 - SMEs may be more amenable to entering data into the survey if they know how their data will be used.
- **Develop a data analysis plan at project inception**
 - Provides guidance to SMEs regarding how their information will be analyzed and reported.
- **Develop a data quality assurance plan prior to data collection**
 - Anticipate which fields might result in inaccurate or incomplete data and make corrections.
 - Allow for corrections during the data collection process.
- **Pre-populate fields to reduce data entry burden**



Marketing and Communications

Develop a strong marketing and communications plan focused on "value added" of the project...

- **Gain affiliations with well-respected organizations**, groups, or publications.
- **Develop reports early** on in the project to demonstrate how the information can be of use.
- Take every opportunity available to **present your project to groups**. Reach as wide an audience as possible.
- **Have well documented, targeted and consistent materials in place** to convey to stakeholders a standard message about your activity.

Logistics

Involve the entire team in resolving ongoing project challenges ...

- **Use wall-sized timelines and project plans** to keep the team informed about project progress.
- **Use phone or in-person communication** to reach out to stakeholders. Generally, repeated emails asking for the same action are ignored.
- **Be proactive and anticipate resource needs** 6-12 months out "e.g. scheduling meeting rooms in advance."

Key Elements of Registry Success

- **STRATEGY: Built on the foundation of a national strategy** to improve coordination of public health surveillance and biosurveillance.
- **LEADERSHIP: Must inform leadership at all levels**—Engagement with leadership from the branch level to the Office of the Director.
- **RESOURCES: Support dedicated to the mission:**
 - Skilled full-time FTEs and contractors (e.g., informatics lead, epidemiology lead, software developer, business analyst, data analyst, operations support, systems architect, communications specialist).
 - Certified and accredited, enterprise approved, licensed survey software.
 - Database and server support.
- **DEMONSTRABLE VALUE: Improved visibility, and accessibility of information** about agency assets generating enthusiasm among programs.
- **CAREFULLY BUILD THE TEAM:** Build a team based on exceptional skill sets, willingness to adapt to challenges and flexibility.
- **CREATION OF MULTI-FUNCTIONAL TEAMS: Cross trained team members** to perform multiple functions.
- **LEVERAGE USE OF COMMON RESOURCES: Collaborated with other Offices** to share technology, infrastructure and expertise,
- **EFFICIENT COMMUNICATION: Open forum** for communication and **non-hierarchical** style of leadership.

Conclusions

- **Developing a Registry** that will capture information about an agency's surveillance assets **is a complex undertaking** with numerous challenges related to technology, human resources, stakeholder engagement, leadership buy-in and marketing.
- **A number of factors play into the success** of such an effort including the use of **strong project management practices**, 1:1 stakeholder **communication** and demonstrating value using **effective marketing** strategies.
- Lessons learned from this effort can serve as "best practices" with widespread application for other agencies/organizations that want to establish a more comprehensive view of their surveillance or other cross cutting assets.

