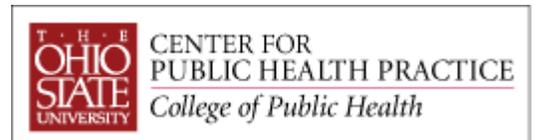


Ohio Pandemic Influenza Public Engagement  
Demonstration Project<sup>ⓧ</sup>  
Mass Fatality Management

Final Report

August 2009



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## Executive Summary

The Ohio Pandemic Influenza Public Engagement Demonstration Project was initiated to support the development of response and recovery plans to manage the consequences of mass fatalities due to an outbreak of pandemic influenza in Ohio. With funding from the Ohio Department of Health, the Ohio State University College of Public Health's Office of Workforce Development worked collaboratively with 11 local health jurisdictions in two geographic areas to coordinate the project.

The project's purposes were to:

- Inform and assist state and local level decision-makers involved in pending, values-oriented policy decisions related to mass fatality management (MFM) in pandemic influenza response and recovery planning,
- Evaluate the effectiveness of engaging both citizens-at-large and other stakeholders in public health policy decisions surrounding MFM,
- Increase state and local capacity to effectively engage the public on policy choices in MFM,
- Empower citizens to participate effectively in public decision-making work regarding MFM, and
- Achieve results that enhance public trust in public health decisions regarding policy choices in MFM.

A series of meetings with stakeholders and representatives of the public were held to obtain insights into proposals for the management of mass fatalities. The general lessons learned through the public engagement meetings included:

- The realization among stakeholders and the public that things will be different in an emergency and a recognition of the need for flexibility.
- The importance of local control and the need of the communities to be able to "take care of their own."
- The importance of keeping open clear channels of communication, before and during a pandemic flu outbreak.
- The need for a single, preferably local, authoritative source of information about the extent and seriousness of the emergency.
- The need for the following guidelines with respect to the treatment of bodies:
  - They must be treated with respect.
  - Individuals handling them should be properly trained.
  - Proper records should be kept to ensure proper identification,
  - While people are willing to be flexible, communities have diverse traditions and practices surrounding death and they should be honored, or at least acknowledged, to the extent possible.
- The vital need for education of the public and the individuals identified to help in case of an emergency, both to generate confidence that the government response will be swift and appropriate and to enhance compliance with guidelines.

As a demonstration project, another objective was to learn about the planning and implementation processes. Some of the process lessons learned include:

- Streamline the advisory, planning, and implementation structure.
- Clearly articulate goals for the project as a whole and for all the intermediate activities.
- The community and stakeholders need to be assured that they are adequately represented. Achieving proper representation may require attention to the duration of the meetings, the day and location of the meeting as well as providing incentives to attend.
- Have public engagement meetings run by trained facilitators.
- Separate the facilitation and recording functions for community discussions.

Two additional conclusions were reached in the project, as follows:

- The structure and flow of the engagement meetings, including access to content experts, presentation of factual information and small group discussions, worked well.
- A recommendation to use OPHAN as an information support and delivery system to support pandemic influenza preparedness.

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## 1. Introduction

### *Project Objective*

The Ohio Pandemic Influenza Public Engagement Demonstration Project was initiated to support the development of response and recovery plans to manage the consequences of mass fatalities due to an outbreak of pandemic influenza in Ohio. This demonstration project proposed to build the capacity of Ohio's local public health jurisdictions, specifically those within 11 rural counties (five-county area in Southeast Homeland Security Sub-Region 1 [as of August 9, 2009, renamed South Central] and six counties within the Northwest Homeland Security Region), to engage the public in discussion about policy decisions related to management of mass fatalities (MFM) due to pandemic influenza. A public engagement process similar to one used by the Centers for Disease Control and Prevention in 2005 and 2006 was applied.

The project's purposes were to:

- Inform and assist state and local level decision-makers involved in pending, values-oriented policy decisions related to MFM in pandemic influenza response and recovery planning,
- Evaluate the effectiveness of engaging both citizens-at-large and other stakeholders in public health policy decisions surrounding MFM,
- Increase state and local capacity to effectively engage the public on policy choices in MFM,
- Empower citizens to participate effectively in public decision-making work regarding MFM, and
- Achieve results that enhance public trust in public health decisions regarding policy choices in MFM.

The Ohio State University (OSU) College of Public Health's Office of Workforce Development (OWD)<sup>1</sup> worked collaboratively with 11 local health jurisdictions in two geographic areas to coordinate the project. Faculty at The Ohio State University's John Glenn School of Public Affairs and the Collaborative for Enterprise Transformation and Innovation (CETI) in the College of Engineering provided evaluation design, implementation and consultation, data analysis, and process study<sup>2</sup>.

Monies from the Centers for Disease Control and Prevention were used by the Ohio Department of Health to fund this project for the period of August 10, 2008 through August 9, 2009. The OWD was the primary grant recipient and was responsible for the management and coordination of the project activities.

This report is organized as follows. The following section provides background information on the counties that participated in this public engagement demonstration

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<sup>1</sup> As of July 1, 2009 this office has been renamed Center for Public Health Practice.

<sup>2</sup> We are grateful to Michael George for his research assistance and help with this report.

project. That is followed by a description of the project structure and its implementation. The data and their sources are discussed next. The main findings and recommendations regarding both the project process and the information gleaned from the public are presented and the report concludes with a summary of these findings and recommendations.

### *Background*

The counties selected for this project represent two rural areas of Ohio: Ross, Pike, Hocking, Vinton, and Jackson Counties in the southeast (combined population of 175,000), and Williams, Henry, Fulton, Paulding, Putnam, and Defiance Counties in the northwest (combined population of 200,000). The population of the five counties in southeast Ohio is between 92 - 98% white; 6% of the population in Ross County is African-American and 1% or less of the population in each of the other four counties is African-American. Vinton County is the poorest in the state with 20% of the population below the poverty line; the other four counties range between 14 and 19% of the population below the poverty line. The northwest counties are part of a larger 18-county Northwest Ohio Homeland Security Region. Here, the population is 95% white and less than 4% African-American; nearly 4% of the population is Hispanic or Latino. The percentage of this population living in poverty is 8.57.

The participating counties in northwest Ohio have worked together for many years and are referred to as the Six-Pact on collaborative projects. The Directors of Nursing, the Health Commissioners, the Environmental Health Directors, and the Emergency Planning Coordinators/Medical Reserve Corps Coordinators meet on a monthly basis to plan and coordinate activities; they are also active in regional planning activities. These counties jointly employ an epidemiologist who coordinates emergency preparedness activities and served as the primary contact for this project.

A similar, though less formal, collaborative structure exists in southeast Ohio. Although the staff from these counties has worked on projects together in the past, they do not have the same level of collaborative history as the counties in the northwest. The Health Commissioner from Pike County served as the primary contact for the southeast Ohio group.

## 2. Project Structure

### *Roles*

The Office of Workforce Development provided primary project management. They established the overall steering committee for the project, finalized the design for the project, and provided assistance to the rural areas to plan and organize project activities. The Office created a facilitation process guide, provided facilitator training, and provided up to four facilitators for the engagement meetings.

The John Glenn School of Public Affairs and CETI coordinated the technological aspects of the project; coordinated the design and implementation of the evaluation process; and conducted data analysis of the processes and organizational arrangements that were necessary to carry out the project, including insights to the replicability of these activities in other contexts.

The local health jurisdictions committed to:

- Provide one Point of Contact for OWD interface
- Identify and convene appropriate jurisdictional work/planning participants
- Contribute to overall project planning
- Identify appropriate facilities/meeting sites in each of the two HLS regions
- Determine meeting dates/times to support optimal participation by target groups
- Identify and communicate with stakeholders and citizens-at-large, assuring inclusion of diverse, at-risk, and special populations
- Design, develop, and disseminate information and messaging appropriate for stakeholder and citizen groups that include diverse, at-risk, special populations
- Identify at least four individuals from each region (total, at least, 8) to participate in facilitation training and serve as facilitators for citizen-at-large and stakeholder meetings
- Assure involvement of appropriate decision makers and dissemination of project findings
- Contribute to interim and final reports by providing unique local descriptions, experiences, outcomes, and lessons learned.

### *Planning*

A primary objective of the initial phases of the project was to ensure that the public engagement aspect of the project was successful in reaching a representative group of the affected populations. To that end three groups were created, one overall Steering Committee, and two implementation teams, identified as Jurisdictional Workgroups (JWG), one in northwest and another in the southeast.

The Steering Committee consisted of a small group of individuals who were familiar with the project objectives, had responsibilities for or expertise in mass fatality management at the state or local levels, and/or had knowledge of the individual communities; their

charge was to offer general guidance to the project. Members represented the Ohio Department of Health's Office of Health Preparedness and legal counsel, the Centers for Disease Control and Prevention, the contributing schools at The Ohio State University, and the northwest and southeast counties' health jurisdictions.

The Jurisdictional Workgroups had broader representation from stakeholder groups, and performed more detailed planning for project implementation, including ensuring that various segments of the community were informed of this public engagement activity and that proper representation of the various stakeholders was achieved. Members of this workgroup included representatives from faith-based communities, mental health agencies, emergency management agencies, hospitals, as well as coroners, governmental decision-makers, and public health officials, and funeral directors. Each JWG was joined by a mass fatality planner from a mortuary response team. JWG members drew upon their own contacts in the community to involve other individuals who might be helpful in reaching the general public.

See Appendix A for a list of Steering Committee and Jurisdictional Workgroup members.

Two meetings - one day-long meeting of the general public (targeting 50 - 100 participants) and one of stakeholders (targeting 35 participants) - were proposed for each region. The agendas for the meetings were modeled after the previously mentioned processes implemented by the CDC for pandemic planning, and included the following:

- Presentation of factual information about pandemic influenza and a fictitious pandemic scenario to provide context,
- Small group (seven to ten participants) discussion of four to five questions about containment measures and response preferences,
- Large group discussion, and
- The use of electronic polling technology ("clickers") that allows participants to anonymously respond to additional multiple choice questions regarding MFM options and have their responses electronically recorded.

Each meeting was followed by a focus group discussion of volunteer participants (target of six to eight individuals) to offer opinions on the process and expected outcomes for the meeting.

The community meeting was planned at least one month prior to the stakeholder meeting to allow for preliminary qualitative data analysis. A brief presentation of the community responses was added to the agenda for the stakeholders. Prior to the meetings, training was planned in each region for representatives from the participating community agencies and from the Office of Workforce Development who would serve as dialogue facilitators at the meetings. Criteria were set for facilitators to help assure objective, neutral facilitation and effective written depiction of the dialogue. The training directly addressed the intent to build capacity within the participating organizations to replicate the process in the future.

### 3. Project Implementation

#### *Facilitator Training Implementation*

Training was developed and delivered in order to prepare representatives from the 11 contributing counties and OWD to facilitate the public engagement dialogues. The training was as follows:

Northwest Ohio	<b>2-hour web-based training:</b> 28 participants	February 17, 2009
	<b>5-hour face-to-face experiential training</b> Emergency Management Agency Defiance, OH: 25 participants	February 24, 2009
Southeast Ohio	<b>6-hour face-to-face experiential training</b> Ohio University Inn and Conference Center Athens, OH: 26 participants	March 31, 2009

The training introduced participants to the project and incorporated instruction on working with large and small groups representing the community while remaining neutral to the content being discussed. Participants practiced facilitation skills using a scenario based on how an actual dialogue might evolve. A novel feature of the training was the introduction of electronic polling equipment (clickers) to be employed at the meetings.

A written participant evaluation was conducted immediately following the training. Prior to each engagement meeting, a 30-minute facilitator briefing was held to review expectations and supportive materials, distribute supplies, and to note any last minute changes. Following each engagement event, facilitators and scribes completed a feedback form to identify what worked, what could have been improved, what was supportive to them, what challenges they encountered, and whether the training was helpful in preparing them for their role in the engagement meetings.

#### *Facilitator Training Evaluation*

Northwest Ohio training participants reported that they were already familiar with the project through their involvement in the planning group and that the 2-hour live web training was not necessary. Based on this feedback, the web-based training was eliminated and brief introductory content was then integrated into the face-to-face training in southeast Ohio.

Overall feedback from the facilitator training evaluation was consistently positive. For both geographical areas, all participants rated their knowledge about or ability to perform ten specific items higher after participating in the training than before. The instructor was rated an average of 4.7 on a 5-point Likert scale. The small group facilitation practice session was mentioned most frequently as the highlight of the training; reasons for this included that it allowed participants time to become familiar and comfortable with the anticipated structure and questions to be applied, to observe others practicing desired

behaviors, to receive feedback, and to acquire skills that will be applicable in other areas of their jobs. A few participants listed application of the electronic polling equipment as new, innovative and useful. When asked about features of the training they would recommend for change (aside from elimination of the web-based session), some participants felt it could have been shorter; a few participants in the southeast training expressed dissatisfaction with the working lunch that was at their own expense<sup>3</sup>.

See Appendix B for facilitator evaluation instruments and data.

*Public Engagement Implementation*

Planning meetings for each area were held in the respective geographic regions at the facilities of contributing jurisdictions. In northwest Ohio, meetings were sometimes held to coincide with other scheduled planning meetings for convenience and efficiency. Table 1 below displays the number of meetings held by each group.

**Table 1: Meetings**

Group	Face-to-Face Meetings *	Conference Calls
Steering Committee	0	2
Northwest JWG	5	2
Southeast JWG	6	2

\* Face-to-face indicates that local participants met in person; OSU may have joined via phone

The work was also supported by numerous e-mails and individual telephone calls between the Office of Workforce Development and the primary contacts within the two rural areas.

**Table 2: Community Engagement**

Northwest Ohio	<b><i>Community at Large meeting</i></b> Defiance, OH 66 participants	Saturday, March 14, 2009 8 am - 3:30 pm
	<b><i>Stakeholder meeting</i></b> Defiance, OH 39 participants	Friday, April 17, 2009 8 am - 3 pm
Southeast Ohio	<b><i>Community at Large meeting</i></b> Chillicothe, OH 63 participants	Saturday, April 25, 2009 8 am - 3:30 pm
	<b><i>Stakeholder meeting</i></b> Chillicothe, OH	Friday, May 22, 2009 9:30 am - 3 pm

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<sup>3</sup> Use of project funds for meals was prohibited by the funder.

### 30 participants

One day long meeting for the general public and one for stakeholders was held in each region (Table 2). Jurisdictional Workgroup members personally recruited participants. Letters, verbal invitations, and follow up phone calls were used to secure commitments from participants. The meeting structure was similar to that of the previously mentioned CDC-supported meetings: general information about pandemic influenza was shared by two JWG members to offer context, and small and large group discussions about possible fatality management strategies were held to gather input and opinions related to implementation of these measures. There was one individual conducting the overall daylong facilitation. Two people, a scribe and a discussion facilitator, were assigned to each of the small groups. The total number of facilitators and scribes varied depending on the number of small groups.

The agenda for the stakeholder meetings included a presentation of the results from the community members' discussions. At all meetings breakfast and lunch were provided. In northwest Ohio, community-at-large participants were given gift cards as an incentive. Pre- and post-tests were given, and a focus group of volunteer participants followed each meeting to gather additional information about the process.

See Appendix C for materials for each meeting.

## **4. Data and Methods**

### *Types of Data*

#### *Small Group Discussions*

In small groups of six to eight, participants responded to a series of questions about mass fatality management strategies, responses and expected reactions. Responses were recorded on flipcharts and subsequently transcribed. Discussion that followed in the large group was also captured on flipcharts. The data from the small group and large group discussions may be found in Appendix D.

We reviewed the data in Appendix D in order to summarize the basic feedback to each question relevant to policy-makers. Although some of the public feedback is likely to have been lost or misinterpreted as it passed through the filters of transcription and then summarization, efforts were made to capture the public feedback as accurately as possible without losing any important information. We analyzed the data in order to identify, first, areas where there were recurring concerns or where significant time was spent in the discussions. Second, we sought to identify the degree of consensus or disagreement around each of these issues. Third, we sought to identify points of concern that may require further action or more information.

#### *Facilitator Summaries*

At the end of each of the daylong public engagement sessions and each of the daylong stakeholder engagement sessions, facilitators were asked to answer questionnaires designed to capture summaries of the information gleaned as well as other reflections. The questionnaires prompted facilitators to identify issues and concerns for which significant time was spent in discussion, there was significant disagreement, or there was a shift in opinion. The questionnaires also prompted facilitators to identify issues of concern, areas where more information was needed from the public, and actions steps. The facilitator summaries are located in Appendix E.

The facilitator summaries served to highlight and summarize salient information from the small group discussions. These summaries were reviewed and incorporated into our analysis of the small group discussions.

#### *Electronic Polling Data*

Electronic audience response devices were used to capture the large group's responses to a subsequent series of questions about their potential reactions during an influenza epidemic. Large group electronic audience response questions may be found in Appendix F.

### *Post-Meeting Focus Groups*

Responses to focus group questions about the engagement meetings and the process were recorded and reviewed. Focus group questions and notes are located in Appendix G.

### *Survey Instruments*

Pre and post surveys were conducted with all audiences to ascertain knowledge gained, societal values, and basic demographics. Pre and post survey instruments may be found in Appendix H.

### *Facilitator Feedback Instruments*

After each meeting, facilitators filled out feedback instruments to capture strengths and weaknesses of the facilitation process. The facilitator feedback instruments are included in Appendix I.

### *Planners Debriefing*

Several of the planners involved on the JWG's participated in a debrief meeting in northwest Ohio towards the end of the project. A similar debrief meeting was held via a conference call for planners from southeast Ohio. Finally, individual telephone interviews were conducted with some planners to obtain their impressions of the process.

## 5. Community and Stakeholder Feedback and Recommendations

The public engagement sessions were designed to elicit feedback to address several specific issues, which are likely to arise in a mass fatality event. These issues, which guided the small group discussions, are listed below.

This section is organized around several themes that emerged from analysis of the real time notes from small group and large group discussions. Facilitator summaries of the small group discussions were also reviewed and incorporated into the analysis. Responses to each of the issues below are addressed within the themed analysis.

1. What are the public's concerns with respect to temporary body storage options?
  - What are acceptable locations for a temporary storage facility?
  - What concerns do people have about delayed burial?
2. What are the public's concerns with respect to delayed removal from the home?
  - What are some public concerns with respect to non-traditional transportation of bodies?
  - What is public an acceptable time period to pick up the body?
  - Do opinions change for deaths involving children?
  - What information is needed to care for a body until it can be picked up?
3. What are the public's concerns with respect to tracking remains?
4. What are the public's concerns with respect to temporary interment?
5. What are the public's concerns with respect to limitations on funeral gatherings?
  - What are some acceptable alternatives to traditional memorial and funeral services?
6. What are the most important sources and types of support needed in a mass fatality event?
7. What kinds of information are needed?
  - What are the most important sources of information?
  - What are the most important sources of information specifically with regard to cancellations to gatherings?
8. What are the public's concerns about mass burials?
  - When is a mass burial considered to be appropriate?

### *Theme 1. Tracking/Identification*

#### Findings

One of the recurring concerns emerging from the small group discussions of the public engagement sessions was the issue of tracking and identifying bodies, whether for mass burial, temporary interment, or for temporary storage. Public participants repeatedly emphasized the importance of being able to track the body of their loved one as it moved through the Mass Fatality Management System. Mass fatality planners can expect a great deal of scrutiny and public anxiety about identification of loved ones. They do not want the bodies to “get lost.” The public will have expectations of multiple layers of tracking mechanisms to ensure accurate body identification. Respondents also voiced concerns about the complexity of paperwork involved in tracking.

The location of the temporary storage facility was also addressed. The public was vociferously against moving bodies beyond county borders, partly because of tracking concerns. There was a consensus that many people will expect that every county have its own temporary storage facility.

### Recommendations

One action step associated with tracking is the need to clearly communicate the procedures for body tracking and identification. Procedures should be as simple as possible with paperwork kept at a minimum. Clear explanations will build trust resulting in the confidence that will help alleviate anxiety about misplaced loved ones. Second, the public recommends building in multiple layers of tracking safeguards, such as multiple body tags, receipts to families, and an electronic database. As one participant expressed, there should be “no doubt” about the identification of the body. A third recommendation is for authorities to take every opportunity to communicate the plans to the public, emphasizing the simplicity and security of identification and tracking.

### *Theme 2. Burial in Accordance With Personal Wishes and Religious Practice*

#### Findings

Participants expressed a diversity of opinions regarding religious burial wishes. This diversity of opinion is apparent even within this relatively homogeneous group of participants in the public engagement sessions. Many participants expressed a willingness to modify tradition in order to accommodate the exigencies and public health concerns of a pandemic flu emergency. This group generally adopted the attitude that personal wishes should be accommodated as much as possible, given resource and public health limitations. Burial and ceremonial choices should be maximized, but this group would be amenable to limiting their choices as long as the rationale for the restrictions was clearly and consistently communicated. Although people were generally understanding of the potential need to modify burial practices, several concerns were raised and many expected resistance to limitations on burials.

The community members were asked to express their concerns and reactions to several non-traditional burial options, including temporary storage, temporary interment, and mass burials. The option of a mass burial was consistently viewed as an absolutely last resort, given the relatively impersonal nature of such burials. There was some concern about bodies being stacked in a disrespectful way. There was also concern about security for the mass burial site. Finally, some were concerned about visitation and being able to identify their loved one.

Of the remaining options, temporary storage was generally preferred to temporary interment. Concerns expressed with regard to temporary interment included the expense, religious objections, and delayed closure.

The option of temporary storage, while preferred to mass burial and temporary interment, evoked several concerns (besides tracking and identification). First, there was some

concern that burial within a twenty-four hour period was a religious non-negotiable for some. For instance, temporary internment is not tolerable for some Catholics because exhumation is not acceptable. It was noted that some people might prefer an informal or even mass burial to storage.

Second, many had questions about the potential option of cremation. Some members of the public noted the limited capacity of crematories, but others were unaware that crematories generally take several hours to clean ashes so that bodies are not mixed. Some were open to non-traditional cremation, such as accelerated or mass cremations. Others noted that cremation was absolutely not an option for members of some religious faiths, such as the Jewish population. For still others, cremation must be done according to specific custom.

Third, participants expressed the expectation that many in their community would prefer to bury their own loved ones than to have bodies handled by the government. If resources do not allow for prompt, traditional burial, this group would strongly prefer to rely on their own support network and resources to bury the bodies on their own property. This attitude, characterized by valuing of self-reliance and resistance to non-local intervention, is pervasive in the public engagement discussions.

Another preference expressed by the public was for local burial. Participants did not want bodies to have to be transported beyond county limits. They prefer that sufficient local land be designated as a cemetery. They would also prefer that only local assets, such as refrigerated buildings, be used as a temporary storage facility. One respondent noted that people would be especially sensitive to children being buried far from home.

Fourth, people were concerned about the ability to visit loved ones in a temporary storage facility.

Fifth, people were concerned about the handling of personal belongings and possessions with such a temporary storage facility.

Finally, people were concerned about decomposition and whether or not they could eventually have an open casket funeral. People will be concerned about the rate of decomposition and options, such as embalming or freezing, for delaying decomposition. Concerns about an open casket will have to be addressed if there is a possibility that bodies will be stored beyond the point of noticeable decay.

In addition to concerns about temporary burial options, participants were asked to express their concerns regarding limitations on memorial services and to list acceptable alternatives to traditional memorial services. As with limitations on burial, limitations on memorial services would be facilitated by clear, consistent communication. Also, some expressed a preference that any limitations be communicated through local authorities in conjunction with local religious leadership.

Smaller gatherings (i.e. immediate family only) seemed to be the most acceptable alternative to traditional memorial services. There was mixed opinion on whether it was acceptable to hold services without the body present. Many felt that video teleconferencing or web-based memorial services was too impersonal, although some felt that such an alternative would be acceptable if necessary. Similarly, some participants, but not most, were willing to have their memorial service conducted over a dedicated television channel.

In sum, a significant percentage of the population will be willing to modify their burial and ceremonial practices, provided there is adequate communication and they are kept properly informed. A theme that emerged from these meetings was that clear, consistent, trustworthy communication is vital for the public to understand and accept any limitations on burial and memorial practices.

There is evidence in the facilitator summaries to suggest that people will follow their own moral compass as to how to handle a burial. For example, one mother expressed that she was torn between wanting to follow the guidelines out of concern for public health and not wanting to out of concern for her children's mental well-being. Many, within the community, appear to be willing to comply with guidelines and mandatory requirements. This willingness to comply will alleviate some of the public health threats and the strains imposed on the fatality management system during a pandemic flu. However, planners should be prepared for a substantial percentage of the population to resist guidelines or even mandates.

### Recommendations

Several participants noted that all religious groups were not represented at the public engagement sessions and that there might be some for whom there will be non-negotiable religious memorial practices.

One potential action step associated with this theme is gathering more information about religious preferences. Planners may benefit from more precise understanding of the expected rate of compliance with burial and ceremonial restrictions. There is also a need for more information about specific religious preferences so that planners understand what practices are non-negotiable, what practices are flexible, and for whom. One suggestion was to create a database of burial preferences ahead of time.

Also, consultation and relationship building with religious leaders will be valuable for communication and consolation purposes. It was suggested by some stakeholders that building the necessary relationships with religious leaders before a pandemic occurs is advisable.

Another action step is to develop plans for addressing the desire for families to bury their own relatives. One option is to create a legal framework that allows such burial by families. If this is not an option, policy-makers need to make decisions about the strictness and mechanisms of enforcement.

### *Theme 3. Respectful Treatment of Bodies/Training of Handlers*

#### Findings

The public wants the plan to contain assurances that bodies will be treated “with dignity.” First and foremost, this means that all handlers of the body are appropriately trained to be sensitive and respectful. One participant wanted the care given to the bodies to be “personal” in contradistinction to an impersonal, mass-production process. Others were concerned about the respectfulness of other aspects of the process. For example, some expressed concerns about the physical condition and security of the temporary storage facility. Participants also worried about the bodies “being stacked on top of each other” or put “on a shelf.” The public also expressed concerns about the implications of the particular methods of storage for body decomposition, and will want to be assured that everything possible is being done to aid in preservation.

Another sub-theme regarding the handling of bodies was the issue of non-traditional transportation. The participants expect those who transport the bodies to be trained to be appropriately sensitive and respectful. The participants did not define respectful treatment to mean that that deceased bodies be transported exclusively by traditional funeral vehicles. They understood resource limitations and were open to the use of alternative vehicles, provided the vehicles are appropriately marked and that the physical handling of the bodies was conducted respectfully.

The public also expressed several concerns regarding the issue of delayed removal from the home. The public generally prioritized prompt removal of bodies ahead of vehicle type. Several of them expressed that delays in removing the deceased from the home that exceed a 24-hour period would not be viewed as reasonable and would cause emotional distress. This concern is emphasized if there are children in the household.

#### Recommendations

The public will be especially concerned with the training of handlers related to respect for the body and sensitivity to the grieving process. The public’s concern for respectful treatment of the bodies will be relevant to both the initial transportation and to whatever alternative to traditional burial is chosen. To address these concerns, the state should develop a training procedure that can be adapted to all types of personnel, including volunteers and health care professionals, who are expected to be involved in handling bodies. We also recommend that the state be sensitive to these concerns in communicating various aspects of the plan to the public.

Also, while some are more flexible, many participants felt that a 24-hour period is the maximum acceptable time period for removing the body from the home. If resources do not allow for removal within 24 hours, planners will need to decide how to prioritize body removal. For instance, the removal management process may allow priority to families with children or may include some type of questionnaire to determine priority removal.

#### *Theme 4. Modes of Communication*

##### Findings

Several members of the public gave feedback about their preferences for the nature of the message delivery. First, the public will expect clear, consistent, non-sensationalized information. The tone should be sober. As one participant noted, they want to be spoken to “like an adult.” Secondly, the source should be credible. Several participants noted that information would be most credible if delivered by a local source such as the local county health department. Thirdly, many participants seem to expect to have access to a hotline and a web site, both of which should be capable of providing information relevant to all aspects of the process.

Participants were asked to identify their primary and secondary sources of information. The sources of information cited included local and state health department web sites, television, radio, local newspapers, flyers, church leaders, church bulletins, postal service, e-mail, and word of mouth from friends, neighbors, and family. The gamut of communication media was listed, and the nature of the discussion was not conducive to identifying the relative importance of any particular medium.

##### Recommendations

In order to facilitate compliance with guidelines and mandates, communication should emanate primarily from local authorities. Local communication should also be as consistent as possible with state and federal guidance.

Participants expressed that they expect to have access to a hotline and a web site if they need additional information. The Family Assistance Center should also have the capability of providing comprehensive information. Planners should decide how to accommodate these expectations.

#### *Theme 5. Communication Content*

##### Findings

The public viewed communication as a critical aspect of the mass fatality management system. The main value of communication, as one participant noted, is that proper communication reduces uncertainty and enhances trust, thus reducing anxiety and increasing the likelihood of compliance. Another participant noted, “The more I learn, the better I feel about it.” As an example, another participant expressed that they would be more willing to move the deceased body while waiting for transport if they felt informed about sanitation and what to expect in terms of decomposition.

There are several content areas, through each step of the process, for which the public expressed desire for information. The public will want to know burial and ceremony options and the rationale for any limitations on those options. They will want to know the procedure for transportation and have assurance that the transporters are properly trained. They will want to know what to do with the body if there is any delay in

transporting the body from the home, specifically with regard to sanitation, decomposition, and equipment. The public will want to know about how their loved ones will be tracked and identified, legal and insurance-related requirements, the procedure for retrieving the body, visitation options, options for storing and retrieving personal items, and the nature of the storage facility and its staff. Finally, the public will want to know of personal options for mental support, with special regard for children.

In addition to communication with the public at large, participants emphasized the value of having personal access to information pertaining to specific cases.

### Recommendations

Appropriate officials should review the public's informational needs regarding each aspect of the mass fatality management process and incorporate the findings above. Once information is reviewed and plans are solidified, one potential action step is to develop trial informational packets to be distributed in future public engagement sessions for additional feedback.

The public recommended that the Family Assistance Center (FAC) have up-to-date and accurate information. The public also recommended the creation of an information packet with a list of things to do and things not to do as well as an expected timeline of procedural events. The public also suggested the creation of a dedicated hotline and a web site, each capable of delivering up-to-date information. They expect the media to act as a resource for alerts and emergency broadcasts.

Although this recommendation did not emerge from the public participation, it seems appropriate to add here that a map based information system that displays the locations of important sites and emergency routes would be useful in supporting pandemic influenza preparedness planning. The Ohio Department of Health has, in OPHAN, the capacity to develop such an information system that can be made available for local use.

### *Theme 6. Pre-Education/Pre-Planning*

#### Findings

Another theme emphasized by both the community-at-large and the stakeholders was the value of education prior to a pandemic outbreak. Education was mentioned as a way to facilitate acceptance of delayed or alternative burial practices. People felt that they would be more comfortable if they knew what to expect ahead of time.

Education was also mentioned by several participants in the context of discussion of the grieving process and emotional support. The public recommended educational outreach to religious leaders and social support services prior to a pandemic outbreak. Also, the public recommended outreach to volunteer organizations to assess their potential role in a pandemic outbreak in activities such as social support, body transportation, or help with body management.

Although the public recommended education ahead of time, there is a need to explore what specific education initiatives would be valuable. One facilitator noted that most people are not tuned in to pandemic flu information before an outbreak occurs. If that were the case, there would be limited value to education initiatives in advance of an outbreak. Those who would pay attention to such education would be the same people who would be most responsive in the midst of the pandemic, leaving very little value added.

### Recommendations

We find that consultation, prior to a pandemic, with stakeholders such as religious leaders and other social support groups is advisable. While many stakeholders have already been engaged as part of this project, a wider range of stakeholders should be consulted as plans develop. The objective of such consultation will be to explore the potential role for various support networks in managing mass fatalities. Another aspect of stakeholder engagement will be education. As plans crystallize, planners can explore the specific content and target groups of educational initiatives.

### *Theme 7. Help with Attaining Closure/Grieving*

#### Findings

The participants were especially concerned with how plans would affect the grieving process. Participants worried about “delayed closure” and “extended grieving” caused by delays in traditional burial practices or other difficulties in interfacing with the mass fatality management system. Delayed closure was one of the main reasons the public expressed concern with modifying traditional funeral practices. Several participants from the public were open to televised or even internet-based funerals as a substitute for a physical gathering. Others expected resistance to any restrictions on funerals.

The public was also concerned about how the location of a mass burial site or temporary body storage facility would affect closure after the pandemic. They preferred trailers and defunct warehouses to schools or other facilities frequented by people or integral to daily life.

#### Recommendations

The main recommendation emerging from these discussions was that religious leaders and social service agencies be enlisted prior to the event in order to plan for their role in aiding with the grieving process. Religious leaders, for example, would be able to provide valuable information about which aspects of the burial process are adjustable. The public also identified social service staff as a potentially useful resource for helping family members through the grieving process.

## 6. Evaluation of Process

One of the purposes of the evaluation was to document the process used to implement this demonstration project so as to learn lessons should the process be replicated. This section presents the main findings to this end, based on a review of notes from debriefing sessions among planners, post-facilitation feedback forms, facilitator training evaluations, and other informal interviews with project managers and planners.

### 1. *Planning Structure/Expectations of Planning Groups*

In accordance with the proposed project structure, one Steering Committee was established to serve an overall advisory function, and Jurisdictional Workgroups that included representatives from various community stakeholder groups were formed in both northwest and southeast Ohio to operationalize the project. In implementation, there was significant overlap between the Steering Committee and the JWG, thus blurring the distinction in intended roles between the two groups. To varying degrees sub-groups to the JWG emerged within each region, and it was this core group of public health jurisdiction representatives that ultimately served as the primary engagement implementers. This further diluted the roles of the Steering Committee and JWG.

Although most members of the Steering Committee and the Jurisdictional Workgroups were satisfied with the process, dissatisfaction with the redundancy in planning function was emphasized by one county official who described it as “one too many levels of planning”. He/she felt that the Steering Committee added little value, except for the participation and expertise from Bobbie Erlwein from the Centers for Disease Control and Prevention.

The need for clarifying the goals and objectives of the project and specific meetings, and for identifying individual responsibilities early in the process cannot be overemphasized. This was evident from both administrative and implementation perspectives. There were multiple project stakeholders - various units within the Ohio Department of Health, two units within The Ohio State University, the local agencies, and regional subject matter experts. Additionally, the project required an exemption from the Institutional Review Board at the university, which necessitated that drafts of recruitment and engagement meeting documents be created prior to initiation of any activities, creating an added urgency to the early timeline. From a local planning and implementation standpoint, people like to know what they are committing to and seem to like to know in advance the purpose of a meeting. One county official noted that clear expectations needed to be laid out ahead of time for the roles and deliverables expected of each planning group.

Should this engagement project be replicated, consideration should be given to combining the Steering Committee and Jurisdictional Workgroups representation and function that existed in this demonstration project into one overall advisory group, leaving the planning details and implementation tasks to a core group of individuals. Expectations of all contributors should be clearly established initially and then revisited throughout the duration of the project.

## *2. Preparation of Facilitators*

Feedback from facilitators about their preparation, found in Appendix B and Appendix I, was consistently positive. Facilitators noted several aspects of their preparation that were valuable, including knowledge of the discussion questions, the opportunity to review the incipient regional plan prior to the event, sample scripts of how the facilitator can address the group, and knowledge of the overall objectives of the project. Facilitators cited the dry runs as especially helpful for knowing what to expect. The “Ground Rules,” a set of discussion guidelines to be followed by all discussion members, were also cited as useful in managing the discussion.

Several facilitators did not think that the web-based facilitator training was necessary. This recommendation was immediately implemented and the second training in the southeast did not include the web-based component.

## *3. Small Groups Worked Well*

There was general agreement that the process by which a larger group was broken into smaller groups of 6-8 people was beneficial. The small groups allowed everyone present to have the opportunity to voice their concerns. Feedback from facilitators indicates that people felt comfortable and were willing to be candid despite the personal subject matter. Also, by having the small group facilitators share discussion summaries with the larger group, everyone could hear what the rest of the small groups had to say. Obviously, breaking into smaller groups may not be ideal if the larger group itself is too small.

## *4. Providing Pandemic Flu Information Useful*

Several facilitators noted the value of the pandemic flu Power Point presentation. The presentation served to make the context more immediate and real, thus facilitating feedback from a more contextualized mental state.

Although the presentation itself was valuable, there was some debate about the value of testing participants’ knowledge about a pandemic influenza. It is our assessment that the pre-post questionnaire on knowledge, while it may have been designed to determine the knowledge base of the participants and to get an idea of how the presentation improved their understanding of the issues, was particularly useful in that it helped focus the attention of the participants on the issues. Whether people learned and retained any information from the presentation is of secondary importance and perhaps only the post test might be necessary to help focus attention.

## *5. Managing the Small Group Discussions*

Several facilitators commented that one of their main challenges was keeping the discussion “on task.” One facilitator noted that people were passionately engaged, and there was a tendency to “get set on a certain issue.” It was a challenge to know how to

intervene to move people on to the next topic. Another emphasized how important it was to really keep track of the time. There is a balance to be struck between allowing relatively open-ended responses so as to not preclude valuable information while also being cognizant of the time.

#### *6. Scribes Extremely Valuable*

Several facilitators noted the challenge of transcribing notes in pace with the rate of discussion. There were several comments appreciating the value of having a facilitator as a separate role from the role of the scribe. When comments are flowing quickly, it is important for the facilitator to be able to focus on the content of the discussion rather than on keeping track of the comments and writing them down. As was noted by one facilitator, an effective system is for the facilitator to verbalize a condensed summary of a participant's comments before the scribe writes it down. The person who made the comments can therefore make sure the condensed summary captures the crux of the thought.

#### *7. Floating Experts Valuable*

Several experts, including an epidemiologist and a mortuary response team member, were available to answer questions during the small group discussions. Facilitators noted that having these experts available was valuable because they were able to help clarify the scenarios and respond to factual questions.

#### *8. Timing and Length Issues*

The vast majority of facilitators felt that the engagement sessions were of appropriate length and “flowed very smoothly.” However, some facilitators did feel rushed to get through all the discussion questions. Also, one facilitator felt there was not enough time to summarize the findings from the small group discussions before presenting to the larger group. In order to save some time, it was suggested that the informational presentation could be condensed and that the electronic responses could be conducted more expeditiously.

#### *9. Noise Needs to be Managed*

Some facilitators commented on the limited space, which forced groups to be in close proximity. In some instances the noise created by multiple small groups in one location became an issue. It may be beneficial to divide small groups into separate rooms.

#### *10. Overall Project Timeline*

A longer project timeline may have allowed for better recruitment. A longer project timeline may also allow for better overall coordination and refining of discussion topics.

## *11. Representation*

Resource constraints limited the size of the stakeholder engagement meeting to thirty-five. With five or six counties represented, not every possible stakeholder could be included in the meeting. One county official felt that a broader range of stakeholders could have been invited, such as morticians from their own county.

The representation of the community-at-large engagement sessions was also limited somewhat by resource constraints. The community members attending the public engagement sessions did not comprise a random sample of the population. As is reflected in responses in Appendix H, the sample of people willing to spend an entire day in these discussions is representative of the subset of the population that is highly civically engaged. These relatively highly civically engaged people may be more amenable to certain types of government involvement or more predisposed to trust government than the average person from these regions. Second, younger populations are underrepresented. Third, it was pointed out in a post-meeting focus group that not all religious groups were represented. Representation may be improved somewhat with a longer timeline, by varying meeting day, times, and durations, and by offering incentives.

## 7. Replicability

### 1. Valuable Information Collected

One of the primary objectives of this project was to inform and assist state and local level decision-makers involved in pending, values-oriented policy decisions related to MFM in pandemic influenza response and recovery planning.

This project yielded valuable information to gauge the opinions of the citizenry and much was learned about people's views on how to manage mass fatalities. It is unlikely that repeated implementation of this project will yield much more new information because there is not much variation in the preferences. However, it is recommended that this project be replicated across the state because the issues discussed in this project are of deep concern to the citizens. It is important as the government plans for major emergencies that the public be kept informed of these plans and that, when relevant, the public should have the opportunity to participate in the decision making. Such local autonomy is in keeping with the Home Rule governance structure of the state.

At this stage in the process, it is not clear what other specific pieces of information will prove the most valuable. Not enough time has passed for the information to be fully reviewed and incorporated into the planning process. Minor changes in plans, including the name of the temporary storage facility to a more sensitive acronym have already occurred in northwest Ohio.

However, several project planners felt that this information will be useful as they move forward in the planning sessions. Several planners mentioned that they fully expect to review the public feedback and take it under advisement. One county official has already met, for example, with members of the clergy after having received feedback from this project about the importance of psychological support from clergy. Other officials expressed that they plan to use the public feedback by sharing the report in planning sessions with local stakeholders. Once appropriate stakeholders review the report, officials expect to consider next steps based on the feedback. Next steps may include mailing a summary of the feedback to participants or posting the feedback in the newspaper or on a website.

Additional objectives included:

- Evaluate the effectiveness of engaging both citizens-at-large and other stakeholders in public health policy decisions surrounding MFM,
- Achieve results that enhance public trust in public health decisions regarding policy choices in MFM.

It is too early to discern the ultimate effectiveness of these engagement projects. Having heard the main concerns of the public, we can expect that the plan will be shared with the participants and the public and will therefore address these concerns and build trust.

## *2. Public Engagement Model Can be Reused*

Two other objectives of this project were to:

- Increase state and local capacity to effectively engage the public on policy choices in MFM,
- Empower citizens to participate effectively in public decision-making work regarding MFM.

In our assessment, this project has met these objectives. One of the main benefits from this project is the creation of a model for public engagement, should other counties decide to gather public feedback related to mass fatality management or even other public health issues. The project was designed so that the OWD provided process guidance, training, logistical support, and engagement meeting facilitation, while allowing the local representatives to have ownership. Comments from debrief sessions indicate interest in replicating this public engagement model. One county official expects to be able to reuse the basic process in other public health contexts. Another county official noted that the Association of Ohio Health Commissioners and Ohio Department of Health are already planning to use this engagement process (large group, small group, electronic polling) in a meeting with all the local health departments in the state to plan for H1N1. Another county is discussing the use of this process for a public engagement project related to family planning. One county official is in the process of looking for funding for electronic polling devices to use them in the future.

The creation of a training course for facilitators represents a significant step in building local capacity to engage the public. Based on the facilitator training evaluations, which show high satisfaction with the preparation, the facilitator training model can be replicated.

## *3. Need for Ongoing Refining of Discussions*

Moving forward, it will be important for planners to review public feedback in order to refine discussions. This project is the first step in an iterative process. As a consequence of this dialogue, additional questions were generated for which policy may need to be defined. As more plans become crystallized, different questions will need to be asked and answered. Also, some questions may have been satisfactorily addressed and do not need to be repeated. At some point, full public engagement sessions may not add any new valuable information, simply because planners already have enough information to make appropriate policy choices.

## 8. Summary

The project yielded two important insights. One, the participants appreciated being involved in the planning and decision making regarding what was considered to be an important public and personal policy issue. Two, people understood the need to be flexible in case of an emergency.

A number of valuable lessons about the process and individual preferences emerged from implementing this project, which we reiterate below.

### *Individual Preference Lessons*

This demonstration project yielded valuable information about the main issues that people care about, and the next step is garner more specific information, relevant to a local context. Some of the general lessons learned included:

- The realization among stakeholders and the public that things will be different in an emergency and a recognition of the need for flexibility
- The importance of local control and the need of the communities to be able to “take care of their own”
- The importance of keeping open clear channels of communication, before and during a pandemic flu outbreak
- The need for a single, preferably local, authoritative source of information about the extent and seriousness of the emergency
- The need for the following guidelines with respect to the treatment of bodies:
  - They must be treated with respect
  - Individuals handling them should be properly trained
  - Proper records should be kept to ensure proper identification
  - While people are willing to be flexible, communities have diverse traditions and practices surrounding death and they should be honored, or at least acknowledged, to the extent possible.
- The vital need for education of the public and the individuals identified to help in case of an emergency, both to generate confidence that the government response will be swift and appropriate and to enhance compliance with guidelines.

### *Process Lessons*

- Streamline the advisory, planning, and implementation structure.
- Clearly articulate goals for the project as a whole and for all the intermediate activities.
- The community and stakeholders need to be assured that they are adequately represented. Achieving proper representation may require attention to the duration of the meetings, the day and location of the meeting as well as providing incentives to attend.
- Have public engagement meetings run by trained facilitators.
- Separate the facilitation and recording functions for community discussions.

Two additional conclusions were reached in the project, as follows:

- The structure and flow of the engagement meetings, including access to content experts, presentation of factual information and small group discussions, worked well.
- A recommendation to use OPHAN as an information support and delivery system to support pandemic influenza preparedness.