Public Input on Medical Countermeasures Seattle & King County

Executive Summary

November 2011

US Department of Health & Human Services Office of the Assistant Secretary for Preparedness & Response Division of Medical Countermeasure Strategy & Requirements

with Analytic Services Inc. & The Keystone Center

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SUMMARY

The Office of the Assistant Secretary of Preparedness and Response (ASPR) in the U.S. Department of Health and Human Services (HHS) is committed to obtaining broad public input on issues pertaining to medical countermeasures (MCM). In order to gain direct public input on MCM distribution and dispensing, the Division of Medical Countermeasures Strategy and Requirements (MCSR) in ASPR conducted a series of public meetings in Seattle and King County, Washington. The community engagements took place in the metropolitan Seattle area on November 5-6, 2011.

The purpose of this public engagement initiative was to develop an understanding of the goals, needs, and behaviors of the public in response to an incident, with the aim of informing national policies and strategies regarding distribution and dispensing of MCM. These MCM strategies are intended to enhance the public's timely and efficient access to these medications when and if directed by public health authorities. The objectives were to leverage input on factors that would influence actions and decision-making during a public health emergency, to inform the development and selection of- and best practices of dispensing strategies; and to identify factors that must be addressed in developing best practices and utilization policies for timely access to medical countermeasures through informed dispensing strategies.

Members from four geographically, economically, and culturally diverse Seattle and King County communities were engaged in the meetings. Although the initiative was not intended to achieve a statistically significant sample of the community's population, a strategic effort was made to identify and recruit members of the public who may be more vulnerable in the aftermath of a public health emergency due to limitations such as mobility, language barriers, complicating health issues, and others. These sessions totaled 330 members of the public.

During the meeting, participants were presented with information about a fictitious intentional anthrax release. Meeting participants were asked how they and other individuals might respond to such a public health emergency. Additionally, the meetings sought to discuss community preferences for receiving medical countermeasures (MCMs) following such an attack.

Several themes emerged at the four meetings held in this engagement that may have implications for future medical countermeasure policy. These include:

• There's no one-size-fits-all approach; multiple options are preferred. The public participants were presented different medical countermeasure development and dispensing strategies. Through the small group exercises, different challenges and constraints in the aftermath of an emergency were discussed; thus, while the public may prefer a particular dispensing method, it was stressed that the community should have access to multiple dispensing methods.

- Equitable access to MCMs and personal safety was of highest importance. Participants also cited the need for quick and easy access to MCMs as being the most important factor as the government determines how best to dispense them. Additionally, participants asked that dispensing strategies ensure that people are not put at increased risk of additional anthrax exposure or social chaos (e.g., predatory or mob behavior).
- Medical countermeasures should be free in the aftermath of a public emergency. A majority of participants felt that medical countermeasures should be provided by the government at no personal cost to individuals. However, some did indicate a willingness to pay some amount if they believed they or their dependents were symptomatic or exposed.
- Clear, consistent, timely, messaging is important. Participants indicated that they would look for information in every way possible in the early hours after an emergency. While many participants indicated they felt the media sensationalized information, their first go-to sources were still television and the internet; however, to seek out experts for input. Most participants would likely "channel surf" over time to cross-check information from one source to another. Consistent and honest messaging from expert sources (such as doctors, the Centers for Disease Control, and state and local health departments) is important, particularly in setting realistic expectations about the amount of medicine available, how long it will take to dispense it, and what locations have MCMs available.
- Most community members believe they will follow instructions on how and when to collect medical countermeasures. In general, participants indicated that they would wait for instruction from their news sources and comply with directives regarding MCM dispensing. If the individual felt they or a member of their family had been exposed they were more likely to comply immediately. If they were fairly confident they had not been exposed, they were more likely to weigh the risk of waiting for a period of time (for lines to dissipate, or for symptoms of infection to appear) with the risk of potential exposure while collecting countermeasures from a central location or a healthcare professional.

This effort provides useful data as to how communities may think about and react in a public health emergency such as an anthrax attack; however, given the small sample size further research should test whether these sentiments, behavioral instincts, and values can be generalized to other populations in the U.S.

BACKGROUND

The Office of the Assistant Secretary of Preparedness and Response (ASPR) in the U.S. Department of Health and Human Services (HHS) is committed to obtaining broad public input on issues pertaining to medical countermeasures (MCM). In order to gain direct public input on MCM distribution and dispensing, the Medical Utilization and Response Integration Branch within the Division of Medical Countermeasures Strategy and Requirements (MCSR) at HHS conducted a series of public meetings in Seattle and King County, Washington. The community engagements took place in the metropolitan Seattle area on November 5-6, 2011. The purpose of this public engagement initiative was to develop an understanding of the goals, needs, and behaviors of the public in response to an incident, with the aim of informing national policies and strategies regarding distribution and dispensing of MCM. These MCM strategies are intended to enhance the public's timely and efficient access to these medications when and if directed by public health authorities.

Members from four geographically, economically, and culturally diverse Seattle and King County communities were engaged in the meetings. Although the initiative was not intended to achieve a statistically significant sample of the community's population, a strategic effort was made to identify and recruit members of the public who may be more vulnerable in the aftermath of a public health emergency due to limitations such as mobility, language barriers, complicating health issues, and others. These sessions totaled 330 members of the public.

During the meeting, participants were presented with information about a fictitious intentional anthrax release. Meeting participants were asked how they and other individuals might respond to such a public health emergency. Additionally, the meetings sought to discuss community preferences for receiving medical countermeasures (MCMs) following such an attack.

APPROACH

Under contract by the Government, a team comprised of subject matter experts from Analytic Services Inc. (ANSER) and The Keystone Center designed and facilitated a public input process. The contractors worked closely with a small steering committee of representatives from ASPR and Seattle-area experts representing local, state and federal public health.

Purpose of the community meetings. The meetings were designed with two objectives in mind:

- To gather input on factors that would influence actions and decision-making during a public health emergency, to inform the development and selection of- and best practices of dispensing strategies.
- To identify factors that must be addressed in developing best practices and utilization policies for timely access to medical countermeasures through informed dispensing strategies.

Questions were designed to help participants articulate their views as well as the rationales underlying those views. ASPR recognizes that increased understanding of the public's concerns and underlying values can be beneficial in helping shape the governments' investments in the development of MCMs and the systems that will support their dispensing. The goal was to hear from a cross-section of four geographic communities within Seattle, recognizing that each would likely have its own culture and its own unique blend of perspectives on health-related issues. The community members that participated in these meetings were not a statistical representation of the population of Seattle, nor of the rest of the US; rather, they served as a window into how people in four Seattle-based communities perceived the issues at hand. **Consistent methodology applied at all four meetings.** The contractor developed meeting agendas in consultation with the steering committee to reflect the inquiry's objectives. All four meetings followed the same format with a combination of presentations, small group discussions, scenarios (to help illuminate trade-offs and priorities), full group discussions, and preference polling.

Given the complexity and somewhat technical nature of the subject matter, ASPR provided background information to ensure an informed dialogue with the public. The meetings began with brief presentations on public health emergency response and medical countermeasures, laying the foundation for the day's conversation.

Participants then divided into small discussion groups of 8-17 people. Each small group had a facilitator from the contractor, ASPR, or the Seattle and King County Health Department. Facilitators asked questions about the Fukushima nuclear reactor incident of March 2011, focusing discussion largely on individuals' perceptions of and responses to that event, and on how community members received information at that time. The group again met in small groups to discuss the anthrax scenario, which was designed to aid in understanding likely individual behaviors following such an attack. Pre- and post- meeting surveys, small group discussions, and electronic polling helped to elicit the following consistent, major themes that may inform future MCM policies and strategies. Lastly, the small groups discussed four broad options for dispensing MCMs, highlighting the advantages and disadvantages of each.

Selection of Seattle. Seattle was selected for its culturally diverse communities, strong tradition of citizen engagement, and recent experience with the Fukushima incident in the last year. The four neighborhoods within Seattle were geographically, economically, and culturally different from each other. Each meeting site was accessible by public and private transportation, characterized as located in a safe neighborhood, and provided adequate parking and hygiene facilities.

Participant recruitment. Recruitment strategies focused on identifying gender, cultural, and socioeconomic diversity representative of the community. A special effort was made to recruit individuals that may have difficulty accessing MCMs following a public health emergency. Meetings were held on Saturday and Sunday to ensure that members of the community who work the traditional Monday through Friday work week were able to participate in the discussions. While there were four community sites for the engagements, all people in the Seattle and King County area were invited to participate. Participants were typically assigned to the engagement site most convenient to their residence or that of each participating. Additionally, in a special effort to recruit parents of young children and participants who may have transportation challenges, a limited number of additional \$75.00 stipends were available for those who qualified for a childcare or transportation stipend, or both. Interpreter services were made available for the hearing impaired. Breakfast, lunch and a snack were served.

Role of local public health. The Seattle and King County Health Department was an active partner in this effort to identify a diverse group of participants for each meeting. The contractor developed a list of over 650 individual contacts and community organizations in consultation with Seattle King County Health Department. Over 73 blogs, 470 past public participants (from previous Keystone-facilitated meetings in Seattle) and 663 individuals and community organizations were contacted by the contractor's recruitment team. The Seattle and King County Health Department was instrumental in accessing the Vulnerable Populations Action Team, which proved helpful as well.

RESULTS

The key results are presented below, based on qualitative and quantitative data collected at the community meetings located in four distinct Seattle neighborhoods.

Demographics of participants. As illustrated in Table 1, a total of 330 members of the public participated in the meetings, with 219 of those being women. A total of 123 participants had one or more children under the age of 18 living at home with them, and there was a good deal of age diversity among participants. According to the demographics, those with medically complex situations, the homebound, and those who have difficulty understanding English were all represented within the meetings.

GROUP	TOTALS
Total number of participants	330
Women	219
Participants with children under the age of 18 living at home	123
18-30 years old	73
31-50 years old	123
51-70 years old	119
71 years or older	9
American Indian or Alaska Native	17
Asian	27
Black or African American	90
Hispanic or Latino	12
Native Hawaiian or other Pacific Islander	11
Caucasian non-Hispanic	102
Single	148
Partnered	48
Complex medical needs (e.g. dialysis, oxygen therapy, infusions)	55
Homebound	11
Do not understand English well	36

Table 1. Summary of participant demographics from community meetings.

Pre-Meeting Participant Survey

Table 2a. *Key Results from Pre-Meeting Participant Survey.* Do you agree or disagree with the following statement: It is the responsibility of government to provide easy access to MCMs in the event of a public health emergency?

ANSWER	AVERAGE PERCENTAGE RESPONDENTS*
Strongly agree; the government should be responsible	56.36
Agree	35.45
Neutral (neither agree nor disagree)	6.97
Disagree	0.30
Strongly disagree; the government should not be responsible	0.30
Blank/No response/Didn't answer	0.61
Total	100.00

*averaged percentages of each of four meeting groups.

Table 2b. *Key Results from Pre-Meeting Participant Survey*. In a public health emergency such as a disease outbreak, widespread food-borne illness, or terrorist attack in your area, where would you first look and how would you obtain information to help you make decisions for you and your family. Please select up to six places where you would obtain this information.

QUESTION	AVERAGE PERCENTAGE RESPONDENTS*
Doctor Call	7.20
Doctor Visit	2.30
Emergency Room Call	2.80
Emergency Room Visit	3.80
Employer Call	2.50
Employer Visit	0.50
Employer Email	1.30
Employer Website	1.00
Federal agency such as the Centers for Disease Control and Prevention (CDC) Call	4.00
Federal agency such as the Centers for Disease Control and Prevention (CDC) Website	7.75
Hospital Call	4.70
Hospital Visit	2.65
Internet or Social Media (Website, Facebook, Twitter, MySpace, etc.)	9.45
Local and State Health Department Call	4.25

Local and State Health Department Visit	0.85
Local and State Health Department Website	6.90
Neighbor or Friend Call	6.15
Neighbor or Friend Visit	2.45
Neighbor or Friend Email	1.25
News Media Website	5.35
News Media TV	9.30
News Media Radio	5.15
Police Department Call	4.30
Police Department Visit	0.65
Police Department Website	2.25
Other	0.95
Blank/No response/Didn't answer	0.30
Total	100.00

*averaged percentages of each of four meeting groups.

Table 2c. *Key results from pre-meeting participant survey*. Please select any of the following that apply to you or members of your household: Check all that apply.

QUESTION	AVERAGE PERCENTAGE RESPONDENTS*
Have difficulty getting transportation in the event of an emergency	19.37
Have complex medical needs such as dialysis, oxygen therapy, infusions, etc., which would make it difficult to quickly leave or be away from your community for an extended period of time.	12.39
Homebound	2.48
Allergic to antibiotics	5.18
Allergic to other medications	8.56
Live alone	13.51
Do not understand English well	8.11
Other things that would make it difficult to access medicine or understand directions in the event of a public health emergency, please specify	9.68
Blank/No response/Didn't answer	20.72
Total	100.00

*averaged percentages of each of four meeting groups.

Small group discussion – Key Concerns

In small groups, participants were presented with a fictitious scenario of an anthrax attack in King County to elicit discussion about how individuals would likely respond to such a public health emergency. The scenario began with unclear information about the affected population, essentially requiring every participant to be concerned for his or her own well-being as well as family members and other loved ones in the metropolitan area. Facilitators provided more information about the incident over the course of three progressive mock news installments, gradually disclosing the nature of the attack, the number of people immediately taken ill, facts about anthrax, the location and timing of the attack, how anthrax is transmitted, and simple steps to take to stay safe and get more information. Over the course of the session, facilitators posed questions for discussion regarding likely goals, needs, concerns, and behaviors in an incident. The following issues were discussed by participants:

- Concern for the safety of loved ones and vulnerable individuals.
- Personal safety
- Search for more information, including
 - 1. Nature, location, scale and severity of the attack
 - 2. Who is affected, and who is at risk
 - 3. How the threat is being spread e.g., food, water, mail, air
 - 4. Exactly what to do (and not do)
 - 5. Signs of danger
 - 6. When to seek medical help, and from where
 - 7. Facts about anthrax
 - 8. Where to access any needed medicine
 - 9. Whether and how to volunteer or otherwise be helpful
 - 10. What to do if one does not have a regular doctor, money to pay for a doctor's services, and/or health insurance
- Need for trustworthy information. Participants variously offered the following as trusted sources of information:
 - 1. CDC
 - 2. Local or state public health department
 - 3. Any particularly robust local community blogs
 - 4. Poison control center
 - 5. Nearby university experts
 - 6. News programs
 - 7. Doctor (for information about anthrax, and possibly for information regarding needed medicine)
 - 8. Pharmacist (for information regarding needed medicine, and possible drug interactions)
 - 9. Family and friends
 - 10. U.S. Surgeon General
 - 11. MSNBC and/or CNN

Overarching Themes for MCM Dispensing

When facilitators asked participants to identify the most important factor(s) for the government to consider in determining how best to dispense MCMs in response to an attack, matters of accessibility and personal safety (for oneself and one's loved ones) emerged as the dominant themes in each meeting location.

A) Accessibility -

- Convenience of location
- Ease of transportation
- Equitable distribution
- Cost
- Language barriers.
- B) Personal safety -
 - Risks from public disorder
 - Risks of exposure to the threat
 - Risk of adverse side effects from the medicine

OPTION	ADVANTAGES	DISADVANTAGES
Central location in the community	 Familiar, convenient sites (Lowes, Wal-Mart and Home Depot) Opportunity to ask questions Socioeconomically equitable Efficient, cost-effective 	 Excludes those with mobility and transportation limitations Risk of contamination Possibility of disruption and chaos, bad behavior Possibility of running out of supplies How do you get MCMs for all family members? Would it limit access by undocumented persons? How would you learn about such an event?
Healthcare professional (personal provider, pharmacy, hospital)	 Opportunity to ask questions Trained for emergencies Personal healthcare provider is familiar with one's medical history 	 Uneven access Small setting, long wait, space and personnel may not be equipped for large community-based emergency Will not accommodate

DISPENSING OPTIONS: ADVANTAGES AND DISADVANTAGES IDENTIFIED

OPTION	ADVANTAGES	DISADVANTAGES
		tourists and travelers
Home delivery	 Wait in the comfort and safety of own home Good for vulnerable populations Convenient 	 Person delivering may be disrupted/attacked Person delivering may not have accurate information about the product Possibility of discrimination – affluent communities delivered before poor neighborhoods A 12-hour wait is not fast enough for people who were exposed Does not accommodate the homeless, transient, those in transit Possibility of product misuse There may be distrust of representatives of the government who are delivering the product
Home storage	 Remain in comfort and safety of home Optimal for vulnerable populations, homebound, etc. Built in control and trust of product once it is in the home No delay after instructed to use it Reduces chance of product shortage 	 Cost – self pay vs. government Product may be used incorrectly or prematurely for other purposes May get lost, misplaced May be stored incorrectly (e.g. wrong temperature) Wasteful if never used

<u>Preference polling</u>. Following the small group discussions, electronic polling was employed to establish participants' preferences on many of the questions they had considered throughout the course of the day. Each participant used an individual response card (similar to a television remote control) to answer several questions projected on a large screen. Polling questions asked participants to indicate which factors were most important in getting MCMs for

themselves and members of their household, who should receive them first, how long they would be willing to wait for medicine, what (if anything) they would be willing to pay for it, and their level of comfort with various dispensing options.

FACTOR	AVERAGE PERCENTAGE RESPONDENTS*		
What is the most important factor in getting medicine to you and members of			
your household? (multiple choice)			
Accessibility? (I can get the medicine quickly and easily)	47.12		
Security? (The medicine is safe from theft and damage)	2.88		
Safety? (I am not exposed to risk when getting and taking the medicine)	20		
Trust? (The instructions for taking the medicine are correct and right for me)	7.69		
Simplicity? (I can use the medicine easily; I understand the instructions are easy to understand)	4.81		
Cost (The medicine is free or affordable)	14.74		
Other?	2.56		
Total	100.00		
Who is it most important to get to medicine to first	t? (multiple choice)		
People closest to the point of the anthrax attack (at or close to the mall)	48.08		
Children	8.97		
Elderly	2.56		
Workers who provide public safety services (police, fire, emergency response)	13.78		
Government leaders who make decisions for the community	0.00		
Healthcare workers (doctors, nurses, pharmacists)	19.87		
Workers who provide critical services for society (water, power, transportation)	1.28		
People worried about becoming sick, even if they don't show symptoms	0.96		
Other?	4.49		
Total	100.00		

Table 3a: Key Results from Preference Polling.

If you or a member of your household was at the mall, when would you get medicine? (multiple choice)

FACTOR	AVERAGE PERCENTAGE RESPONDENTS*
Immediately after being told to do so by a healthcare professional	82.69
When I or a member of my household has symptoms	7.05
When I or a member of my household tests positive for anthrax	7.69
I would not get medicine	2.56
Total	100.00
If you or a member of your household had not bee	en to the mall in two
months, when would you get medicine? (multiple	choice)
Immediately after being told to do so by a healthcare professional	51.30
When I or a member of my household has symptoms	24.03
When I or a member of my household tests positive for anthrax	16.88
I would not get medicine	7.79
Total	100.00
How long would you be willing to wait at your hor delivered to you for you and members of your hou	
Not at all.	27.42
12 hours.	20.97
18 hours.	4.19
24 hours.	23.55
36 hours.	9.68
As long as it takes.	14.19
Total	100.00%
How much would you pay for anthrax medicine fo (multiple choice)	r you and your family?
Nothing, it is the government's role to provide medicine for a public health emergency	49.21
Nothing, I cannot afford this for my family	3.81
Less than \$10 per person.	15.24
Less than \$20 per person.	6.98
Less than \$30 per person.	6.98
As much as it takes to keep me and the members of my household safe.	17.78
Total	100.00

FACTOR	AVERAGE PERCENTAGE RESPONDENTS*	
How long would you wait in line at a public location to pick up medicine for		
you and members of your household? (multiple choice)		
Not at all.	13.29	
Up to 30 minutes.	18.35	
Up to 1 hour.	14.56	
Up to 2 hours.	13.29	
Up to 4 hours.	3.80	
As long as it takes.	36.71	
Total	100.00	

Post-Meeting Surveys. Following the polling and the subsequent group discussion, participants were asked to complete a brief survey. The post-meeting survey repeated several of the questions contained in the pre-meeting survey in an effort to understand how participants' knowledge and perspectives may have changed over the course of the day as a result of presentation, discussion and reflection. Table 4 provides select results from the post-meeting surveys.

QUESTION	Ave	rage
The most important issue officials need to consider when making decisions regarding how to make MCMs accessible to me and members of my community is: <i>Please check only one</i> .	Pre-Survey (percent)	Post-Survey (percent)
Blank/No response/Didn't answer	3.33	9.48
Ability to access transportation	20.61	18.35
Distance of my workplace from my home and children	3.94	3.06
Distance of my home to my primary-care or family doctor	4.85	3.98
Number of family members in my household that I am the primary caregiver for	8.18	6.42
Distance and use of locations in the community that provide medications to patients every day such as pharmacies, clinics, etc.	59.09	58.72
Total	100.00	100.0%
If a public health emergency such as a disease outbreak, widespread food-borne illness, or terrorist attack occurred in your area, public health officials may advise members of the community to take medicine in order to be protected from serious illness and death. How do you prefer to get medicine for you and your family? Please check only one.	Pre-Survey (percent)	Post-Survey (percent)

QUESTION	Ave	rage
Blank/No response/Didn't answer	14.89	8.87
Medicine is already stored in your home	17.02	27.52
You pick up medicine at a community location such as a school, your workplace, or a community center		
	22.49	27.83
You pick up medicine from a healthcare professional such as a pharmacist, doctor, or nurse		
	29.79	22.94
Medicine is delivered to your home	15.81	12.84
Total	100.00	100.00

CONCLUSION

The Seattle and King County public engagement demonstrated the continued importance of acquiring information from end-users in the development of medical countermeasure systems and capabilities because it provided key information on needs, goals, and concerns that need to be addressed in this planning- some of which are known, while others previously were not wellunderstood. Medical countermeasure capabilities must be developed with regard to said input such that they enable all users to have timely access and effectively utilize the medical countermeasures available in a national security or public health emergency. Communities are not all the same and therefore one single medical countermeasure deployment/ dispensing/ utilization strategy does not serve the needs of all. A menu of medical countermeasure readiness and dispensing options developed through processes that are well-informed by partnerships and interactions with end-users is the best solution for all stakeholders in building preparedness. Finally, the information gathered in the engagement conducted in Seattle and King County addresses the public needs, concerns, goals, and potential behaviors in an anthrax emergency- in this community. Continued engagements could be valuable to address many threats of concern, as well as the diversity of populations throughout the Nation to ensure that a broad range of planning options are available to all communities.