Public Engagement on Facilitating Access to Antiviral Medications and Information in an Influenza Pandemic: Workshop Series Summary

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Workshop Series Summary

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and Bruce M. Altevogt, *Rapporteurs*

Forum on Medical and Public Health Preparedness for Catastrophic Events

Board on Health Sciences Policy

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Willing is not enough; we must do."
—Goethe

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This workshop summary has been reviewed in draft form by individuals chosen for their diverse perspectives and technical expertise, in accordance with procedures approved by the National Research Council's Report Review Committee. The purpose of this independent review is to provide candid and critical comments that will assist the institution in making its published summary as sound as possible and to ensure that the summary meets institutional standards for objectivity, evidence, and responsiveness to the study charge. The review comments and draft manuscript remain confidential to protect the integrity of the process. We wish to thank the following individuals for their review of this summary:

Terri Hyduke, Children's Physician Network, Minneapolis, MN
Meredith Li-Vollmer, Seattle & King County, WA
Paul Petersen, State of Tennessee Department of Health, Nashville
Jo Ellen Warner, National Association of County and City Health Officials, Washington, DC

Although the reviewers listed above have provided many constructive comments and suggestions, they did not see the final draft of the summary before its release. The review of this summary was overseen by **Herminia Palacio,** Executive Director, Harris County Public Health and Environmental Services. Appointed by the Institute of Medicine, she was responsible for making certain that an independent examination of this summary was carried out in accordance with institutional procedures and that all review comments were carefully considered. Responsibility for the final content of this summary rests entirely with the rapporteurs and the institution.

Contents

Introduction[1]

When—not if—the next influenza pandemic occurs, robust planning will be essential to ensure a successful response in the face of a health care system overwhelmed by thousands or hundreds of thousands of sick people, and those worried they may be sick. Influenza pandemics, such as the 2009 H1N1 pandemic that swept the globe, illustrate the need to plan ahead. One of the challenges public health officials may face is the need to distribute antiviral medications that can decrease the severity and duration of disease to large numbers of people. Distribution and dispensing will need to occur within the potentially limited time frame in which the medication is effective, and persist over a period of time to treat multiple waves of a pandemic.

In response to a request from the Centers for Disease Control and Prevention (CDC), the Institute of Medicine's (IOM's) Forum on Medical and Public Health Preparedness for Catastrophic Events (Preparedness Forum) designed and convened a series of workshops ("community conversations") that explored the public's perception of potential alternative strategies for facilitating access to antiviral medications and treatment advice during an influenza pandemic. Based on its statement of task (Box 1) the workshop planning committee convened members of the general public in three locations—Fort Benton, Montana (MT), Chattanooga,

[1]The workshops were organized by an independent planning committee. The planning committee's role was limited to planning the workshop, and the workshop summary has been prepared by the workshop rapporteurs as a factual summary of what occurred at the workshop. Statements, recommendations, and opinions expressed are those of individual presenters and participants and are not necessarily endorsed or verified by the Forum, the IOM, or the National Research Council, and they should not be construed as reflecting any group consensus.

BOX 1
Statement of Task

In response to a request from the Centers for Disease Control and Prevention, the Institute of Medicine's Forum on Medical and Public Health Preparedness for Catastrophic Events will organize and convene a series of public engagement activities. These activities will explore the public's perception of the safety, feasibility, and acceptability of potential alternative strategies for distribution and dispensing of antiviral medications to the public during an influenza pandemic. Participants will consider the need for, acceptability of, and advantages and disadvantages of

- receiving a prescription over the phone for antivirals from a medical professional other than a patient's usual provider;
- receiving antivirals or other medical countermeasures (MCMs) from a licensed pharmacist;
- obtaining antivirals from a pharmacy during a severe pandemic; and
- increased partnerships among state and local governments, the private sector, and other entities to dispense antivirals or other MCMs.

A single individually authored summary of the public engagement activities will be prepared based on the information gathered and the discussions held.

Tennessee (TN), and Los Angeles, California (CA)—during February and March 2012 to consider the acceptability of several alternative strategies of delivering antiviral medication to the public during a pandemic. These discussions will help to inform potential strategies still in the development stages at the CDC. The public was asked to consider, if an influenza pandemic were to strike, how the normal systems for prescribing and dispensing antiviral medications could be adjusted to ensure that the public has quick, safe, and equitable access to these potentially life-saving drugs and to information about the pandemic and treatment options.

Background

Significant progress has been made in public health and medical preparedness since September 11, 2001. State and local public health authorities are currently responsible for the majority of medication distribution and dispensing activities within their jurisdictions during public health emergencies. During both a pandemic and in routine seasonal influenza, antiviral medications are used to lessen the duration and severity of a patient's symptoms, not to be confused with a vaccine, which is administered to the well to prevent them from getting sick. Vaccines take months to manufacture, in part because they must be specific to the influenza type. Antivirals, on the other hand, can work against many different strains of influenza. Because antivirals are more effective if taken within 48 hours of symptom presentation, many public health agencies have developed preparedness plans to facilitate the rapid dispensing of antiviral medications to large numbers of people during influenza pandemics.[2] However, the feasibility and timeline of these plans remain significant concerns given projections that during a severe pandemic, approximately 30 percent of the population could become ill over a 12- to 18-month period.[3] In such circumstances, the normal channels through which antiviral medications are prescribed, dispensed, and distributed could easily become overwhelmed. Indeed, the 2009 H1N1 influenza pandemic brought to light several related challenges that need to be addressed during future preparedness planning initiatives.

In response, the CDC is exploring alternate delivery systems for antiviral medications during severe influenza pandemics. Potential prescribing, dispensing, and distribution strategies include a variety of nontraditional mechanisms to ensure that people sick with flu receive antiviral medicines in a timely manner. These include

- **Nurse Triage Lines (NTLs):** Phone hotlines that people with flu-like symptoms could call for advice, discuss whether an anti-

[2]For more information, see CDC, *Antiviral agents for the treatment and chemoprophylaxis of influenza: Recommendations of the advisory committee on immunization practices (ACIP)* (Atlanta, GA: CDC, 2011). Available at http://www.cdc.gov/mmwr/preview/mmwrhtml/rr6001a1.htm (accessed May 2, 2012).

[3]Department of Health and Human Services (HHS), *HHS pandemic influenza plan* (Washington, DC: HHS, 2005). Available at http://www.flu.gov/planning-preparedness/federal/hhspandemicinfluenzaplan.pdf (accessed April 18, 2012). Further clarification provided by personal communication with Lisa Koonin, senior advisor, Influenza Pandemic Unit, CDC, February 14, 2012.

viral medication is indicated and, if so, possibly receive a prescription that the NTL would transmit to callers' local pharmacies for dispensing (if feasible). NTLs would be staffed by nurses who would be trained to follow a specific protocol and work under the direction of a physician. In addition to prescribing antivirals, NTL nurses could provide guidance to the caller about whether to seek urgent care, as well as information about how to care for someone with flu. NTLs may be built onto an existing regional hotline infrastructure (e.g., poison control centers) and may leverage other medical hotlines currently operated by health plans, hospitals, and health agencies.

- **Antiviral Pick-Up and Delivery by Community Contacts:** A strategy to encourage family, friends, neighbors, and other community contacts to pick up prescribed antiviral medications from pharmacies and deliver them to people with flu at home. Public health agencies would encourage people who have been prescribed antiviral drugs to ask others to pick up and deliver their prescriptions. They also would educate the public about the benefits of encouraging sick people to stay home to prevent the spread of the virus, and encourage their active support in helping friends and neighbors. More coordinated programs might be set up through local community organizations whose staff or volunteers could provide this service.
- **Pharmacist Prescribing Under Collaborative Practice Agreements:** A system through which a person sick with flu could visit certain pharmacists who would be authorized to prescribe and dispense antiviral medications according to approved protocols developed by influenza experts. Such pharmacists would work under formal "Collaborative Practice Agreements" with physicians who would provide supervision and consultation.

The CDC also is exploring new strategies to communicate clear, accurate information about pandemic influenza and treatment to the public, including

- **Web-Based Tool:** A web site launched during a pandemic for the purpose of helping people sick with flu-like symptoms and their caregivers to decide whether to seek medical care and to advise them when to seek treatment options, including antiviral medications.

- **Text-Messaging Tool:** An opt-in system through which people prescribed antiviral medications could receive text messages containing information about their flu treatment, potential side effects of antivirals, reminders to take their medicine, and other relevant advice.

These strategies are not yet government policy and are still under exploration. Determining the feasibility and acceptability for these alternatives is ongoing with public health officials and private-sector entities. Before moving ahead, however, the CDC recognized the importance of also exploring the public's perception of the safety, feasibility, and acceptability of these strategies. Therefore, it asked the IOM to design and convene community conversations in three locations across the country to engage the public on the five strategies outlined above.

About This Summary

This document is intended to summarize the discussions and key takeaway points at the three community conversations. Unique ideas presented at the workshops are not attributed to individual participants, in keeping with the workshop design that intentionally excluded the recording of personally identifiable viewpoints in order to protect participant confidentiality and create an environment in which these topics could be discussed openly. Situations where several participants made similar points at all three community conversation locations are identified as "common themes." Throughout the summary, themes identified at a specific community conversation are followed by the appropriate two-letter state abbreviation of that location in parentheses. It is important to note that there is inherent variation in the specific discussions that took place at each community conversation, which is attributable to the individuality and diversity of each participant group. Therefore, the absence of discussion on any one specific idea in a particular location does not suggest that those participants were in favor or against that idea. Any opinions, conclusions, or recommendations discussed in this workshop summary are solely those of the individual participants and should not be construed as reflecting consensus or endorsement by the workshop, the Preparedness Forum, or the IOM.

DESCRIPTION OF THE "COMMUNITY CONVERSATIONS"

The purpose of the "community conversations" was to obtain input from a diverse cross-section of the public about the acceptability of possible strategies to facilitate access to antiviral medications during a flu pandemic. The community conversations were designed to

- inform participants about antiviral medications, the challenges of getting them to the public during a flu pandemic, and current planning efforts to address these challenges;
- gather input about the acceptability and feasibility of possible alternative strategies for the quick, safe, and fair prescribing and dispensing of antivirals in a pandemic, and about strategies for informing the public about pandemic influenza and treatment; and
- encourage broad participation that includes members of typically vulnerable and hard-to-reach populations.

The goal of the community conversations was not to promote or reach consensus or agreement. Similarly, the themes generated by participants' discussion during these three workshops cannot be generalized to other populations or communities. Rather, their purpose was to elicit a variety of opinions, concerns, and the participants' own ideas for the CDC to consider in its subsequent policy deliberations. The use of this type of public engagement is ultimately advisory. It can help policy makers understand an array of priorities and values that might be important to individuals and to the public at large, and on what issues people differ and why. It also can alert policy makers to areas of potential misunderstanding or distrust, where greater awareness will have to be fostered to promote public acceptance and cooperation when plans are implemented in an actual public health crisis.

Planning and Participant Recruitment

The IOM was charged with organizing community conversations in three geographically and demographically diverse locations. These sessions were to convene a total of 200 individuals representing a diverse cross-section of the local populations, including people who might need additional assistance in a crisis (e.g., elders, people with disabilities, oth-

ers who routinely face barriers to accessing care). However, these activities are not meant to be a statistical representation of the locations or of the nation. Therefore, any themes identified reflect only the participants and not necessarily the larger community.

The IOM partnered with local public health and community organizations in each location. The role of the local partners was to spearhead community outreach and recruitment of participants and key personnel and to assist in the planning and execution of the sessions. The three sessions were scheduled as follows:

1. Fort Benton, MT: Rural frontier; February 9, 2012; local partners: Montana State University, Choteau County Extension, and Chouteau County Public Health.
2. Chattanooga, TN: Midsize urban; February 16, 2012; local partner: Chattanooga-Hamilton County Health Department.
3. Los Angeles, CA: Large metropolitan; March 2, 2012; local partner: Healthy African American Families II, Department of Public Health–Los Angeles County.

The target attendance were 50 participants in Fort Benton and in Chattanooga and 100 in Los Angeles. The Fort Benton and Los Angeles sessions were oversubscribed (75 and 108 respectively), while the Chattanooga session included 49 participants, bringing the total number of participants to 232. Local partners were provided with demographic recruitment targets for age, sex, race/ethnicity, and education level based on U.S. Census data for their counties. While there was no formal requirement to meet those targets, only Los Angeles did not.[4] The Los Angeles session had approximately 15 monolingual Spanish-speaking participants.[5]

Local partners also were provided with standard communications tools to use in their participant recruitment efforts. The program name used on materials targeted to the general public was *In a Flu Pandemic: Getting Life-Saving Medicines to the Public*. The IOM and the local

[4]The Los Angeles session was intended to draw participants from throughout Los Angeles County. Most of the actual participants, however, were from South Los Angeles and reflected the demographics of that predominantly African American and Hispanic/Latino community.

[5]In Los Angeles, simultaneous interpretation was conducted for the large-group activities. At two tables, small-group discussions were facilitated in Spanish and reported out in English by bilingual table facilitators. Notes were recorded in English by bilingual note takers. Participants received Spanish-language translations of all printed materials, as well as printed copies of the translated Audience Response System and Introductory Slides, described below.

partner organization were identified on materials as program sponsors. An example of the key recruitment messages used can be found in the appendix.

Participants were offered $50 stipends as compensation for their time and to help cover any out-of-pocket costs of attending the session. Stipends also likely facilitated the recruitment process by providing a small incentive to attend.[6]

Agenda and Tools

The IOM planning committee developed a set of program materials to run 4-hour sessions at all three venues.[7] These materials were designed to provide participants with the background and tools they would need to engage in informed discussions about alternative strategies for facilitating access to antivirals in a flu pandemic. The main elements of the agenda can be found in Box 2.

BOX 2
Major Structural Elements of Each Public Engagement Workshop

Introductory Exercise: Small-group table discussions to break the ice, establish ground rules, and introduce participants to the facilitated discussion and report-out method. All participants were invited to state briefly why they decided to attend the community conversation and to identify their greatest hope and greatest fear should a flu pandemic strike.

Audience Response System (ARS) Presurvey: A series of questions about participant demographics and other relevant characteristics, followed by a series of opinion statements related to the proposed alternative strategies for delivering antivirals during a severe pandemic. Participants used electronic response devices (handheld keypads) to respond to questions and statements that were both projected as slides and read aloud to accommodate participants with low vision

[6]In Fort Benton, stipends were not mentioned in the recruitment process; participants first learned of the stipends in the confirmation materials they received after registration. In Los Angeles, stipends were offered during recruitment, but participants were informed at the start of the session that their receipt of the stipend did not require them to stay or participate in the entire session.

[7]The agenda and tools are based on the IOM's model and method for engaging the public on "crisis standards of care" guidelines for prioritizing the allocation of scarce medical resources in pandemics and other major disasters (Institute of Medicine, *Crisis standards of care: A systems framework for catastrophic disaster response* [Washington, DC: The National Academies Press, 2012]).

or literacy. The main purpose of the presurvey opinion statements was to quickly immerse participants in the topic and to focus their attention on the issues that would be considered during the session.

Expert Presentation: A slide presentation providing background on pandemic influenza, antiviral medications, anticipated challenges in delivery of antivirals during a pandemic, and proposed alternative strategies for discussion during the session. The information was targeted to general public audiences. The issues were framed as follows:

- In a severe pandemic, people seeking antiviral drugs could meet many roadblocks:
  - Many people sick at the same time.
  - Crowded hospitals, medical offices, and clinics.
  - Long waits to see a health care provider for a prescription.
  - Sick, contagious people occupying waiting rooms and other public spaces.
  - People not sure where to turn for information.
- In response, possible new strategies are now being developed:
  - To provide quick, safe, fair access to antiviral drugs (nurse triage lines, pick-up and delivery by community contacts, pharmacist prescribing).
  - To offer advice to sick people and the worried well (pandemic flu web site, text-messaging tool).
- We want to hear your views on these potential strategies, and other ideas you might have.

Small-Group Scenario Discussions: Two 30-minute scenario discussions, led by table facilitators, at the core of the agenda. Participants were asked to consider specific questions about the acceptability and feasibility of possible alternate strategies for delivering medications under two sets of circumstances, described in the scenarios as:

- A severe flu pandemic that has led to long delays to see health care providers who can write prescriptions for antiviral medications.
- A point in time during the pandemic when there are no longer enough antiviral medications for everyone in need.

Report-Outs to the Large Group: Following each small-group discussion, brief presentations by table representatives of three key points that table members elected to share with the full group.

Local Partner Presentation: Short presentations by local partners or their designees on public health preparedness planning and resources available to the local community, and an opportunity for participants to receive answers to questions about local preparedness initiatives.

Continued

ARS Postsurvey: After the last group activity, a repeat of the same opinion statements to which participants responded in the presurvey, immediately followed by display of the comparative responses from the pre- and postsurveys for participant reaction and discussion.

Evaluation: A series of statements delivered by ARS to elicit participants' opinions about their experiences and perceived value of the community conversations, followed by written responses to several open-ended questions.

Personnel

Many individuals played key roles in orchestrating and leading the community conversations. Table facilitators and note takers were provided with background and program materials in advance of the community conversations, including a "Guide for Table Facilitators and Note Takers" and a briefing memorandum with additional subject-matter background and suggested answers to anticipated participant questions about pandemics and antiviral medications. The day prior to their sessions, they attended 2-hour trainings where they received further introduction to the topic, agenda, and tools, and participated in a simulation of one of the discussion scenarios. Immediately following the community conversation, they participated in a debriefing. Table facilitators and note takers were paid stipends to compensate them for their time preparing for and attending the community conversations.

Process for Small-Group Discussions

Throughout each community conversation, participants engaged in small-group discussions at their tables about the various questions and issues presented to them, and also reported out and engaged in further discussion with the large groups. Their comments were documented in several ways. For the small-group introductory and scenario discussions, trained note takers at each table recorded key points by writing them on highly structured templates designed for this purpose. For the report-outs on the two discussion scenarios, each table was asked to complete a form on which they wrote the three main points they planned to share with the full group. These forms were collected, and additional note takers recorded the ideas presented by the table representatives in their report-outs and during the ensuing large-group discussions. Finally, most participants completed short written evaluation forms at the end of the session.

In addition to engaging in small- and large-group discussions, participants responded to audience response system (ARS) questions about themselves (e.g., demographic and other personal characteristics such as health insurance status), pre- and postsurvey statements related to accessing antiviral medications in a pandemic, and an evaluation of the community conversation. During these ARS surveys, electronic viewpoints were collected automatically and anonymously by means of participants' handheld response devices.

To preserve participant confidentiality, note takers and the participants themselves were instructed not to record participant names or any other potentially identifiable viewpoints on the note-taker templates or elsewhere. Because the ARS response devices were distributed randomly to participants, the electronic viewpoints cannot be connected to particular individuals.

The information recorded on the note-taker templates from the 27 tables were robust in all but a few instances. Most of the notes were detailed, legible, unambiguous in meaning, and relevant to the topic. Note takers occasionally recorded direct quotes but, as instructed, they primarily summarized and synthesized participant ideas and themes. They appear to have captured predominant themes similarly recorded by other attendees taking general notes during each session (e.g., planning committee members and IOM staff in attendance, local partners' staff). Notes from the report-out sessions were also of high quality.

This summary makes general reference to the ARS pre- and postsurvey viewpoints where appropriate. The primary purpose of these surveys was not to collect data, but rather to engage participants, helping them to focus on the issues at hand. The viewpoints are not detailed in this summary to avoid any possibility that the results could be misconstrued as generalizable to populations beyond the three participant groups. However, changes in the trends of participant responses between the pre- and post-ARS exercises may indicate the potentially positive effects of informing participants about as well as engaging them in the issues.

SESSION SUMMARIES

This section summarizes the characteristics of each community conversation, and describes common themes among the three sites and within each session. Neither the session characteristics nor the identified

themes can be generalized beyond the specific participant populations of each workshop.

Session Characteristics

As noted above, the venues for the three community conversations were selected to reach diverse populations in different regions of the United States. Attendance at each session is broadly described as follows:

- **The Fort Benton, MT, session** was attended by 75 residents of the city of Fort Benton (pop. 1,478) and Chouteau County (pop. 5,765).[8] Consistent with area demographics, participants were mostly white, and included several members of two local Hutterite[9] colonies. The predominant age was higher than that of the other two sessions, with half the participants between the ages of 45 and 64 and none under age 25. Participants had a very high rate of health insurance, and more than 80 percent reported having at least some college education. Nearly one in five participants reported having some type of disability. Although participants who live in Fort Benton have a pharmacy nearby, approximately a third live more than 25 miles from a pharmacy.
- **The Chattanooga, TN, session** was attended by 49 residents of the city of Chattanooga (pop. 168,075) and its surrounding county (Hamilton County, pop. 337,294). African Americans made up about 40 percent of the participants. Chattanooga participants were diverse in age, but had the largest representation of young adults between ages 18 and 24 of the three sessions. Participants' rate of health insurance and level of education were nearly as high as Fort Benton participants, and equivalent numbers (nearly one in five) self-reported having a disability. Nearly all participants lived within 5 miles of a pharmacy.
- **The Los Angeles, CA, session** was attended by 108 residents of Los Angeles (pop. 3,797,144) and Los Angeles County (pop. 9,830,420). The vast majority of these participants live in South

[8]Population statistics source: U.S. Census Bureau, 2006-2010 American Community Survey, 2010. http://factfinder2.census.gov/faces/nav/jsf/pages/index.xhtml (accessed April 18, 2012).

[9]Hutterites are an Anabaptist group who live communally, dress according to their traditions, and speak German within their colonies. Source: Hutterian Brethren, 2012, http://www.hutterites.org/ (accessed April 18, 2012).

> Central Los Angeles, the predominantly African American and Hispanic/Latino community where the session took place. Fifteen participants required Spanish translation and interpreter services. Participants were diverse in age. Nearly half were uninsured, and just over half reported having at least some college education. About one in three reported having a disability. Nearly all lived within 5 miles of a pharmacy.

During the introductory table exercise, participants were asked to describe their reasons for attending the community conversation, and their hopes and fears if an influenza pandemic were to strike. Although these questions do not pertain directly to the sessions' main focus on alternative strategies for accessing antiviral medications, the major themes that emerged offer a window into the mindset that these particular participants brought to the community conversations.

Many participant reasons for attending a community conversation are captured by one of the following themes: (1) to learn about influenza pandemics or antiviral medications; (2) to be prepared for emergencies such as pandemics; and (3) to contribute to the community. Some participants also referenced the offer of a stipend.

When asked about their "greatest hope" in a flu pandemic, the common themes that arose included the importance that antiviral medications and other critical resources be available to everyone, and that through good communication, people know how to get help. Other themes were that communities and authorities will be prepared to respond, the pandemic can be contained quickly, communities will pull together, and panic and chaos will not ensue.

While not implying a consensus, participants' most general causes for concern in a pandemic were the future availability of antivirals and other critical or life-saving resources, and that panic and chaos might ensue. Other site-specific themes included high mortality in general and among family, friends, and selves (CA, TN), ineffective or unsafe antiviral medications (CA, TN), poor communications (TN), inadequate preparedness planning, resulting in slow resource distribution (MT, TN), slow delivery of resources to rural areas (MT), and that the poor and other vulnerable groups will not receive their fair share of resources (CA). Similarly, at the outset of each workshop, some participants were not confident that "the normal ways I get prescription drugs will work well for me" in a pandemic.

Scenario Discussion Points and Themes

As noted earlier, during the small-group scenario discussions, participants were asked to consider two distinct sets of circumstances: (1) a severe pandemic flu in which an antiviral medication is the only known treatment and the normal channels for obtaining and filling prescriptions are overwhelmed; and (2) a point in time during the pandemic when those antiviral medications have become scarce.

The following sections describe the points and themes identified during discussion exercises in which participants were asked to respond to a series of specific questions posed by the two scenarios. All of the information and ideas compiled below are not generalizable to the broader population, and should not be construed as reflecting consensus or endorsement by participants in the community conversations, the Preparedness Forum, or the IOM.

Goals and Values for Prescribing and Dispensing Antiviral Medications

At various points throughout the sessions, participants were asked to reflect on which goals and values are most important for policy makers to advance when developing alternative strategies for prescribing and distributing antiviral medications during a pandemic.

Some of the themes delineated below reflect responses to direct questions about goals and values, while others are based on ideas that emerged in the course of discussion of other issues. The common major themes are presented alphabetically; their placement in the list does not signify their degree of importance or any other rating or rank.

Participants discussed the goals and values that should drive policies and individual actions during a pandemic when people with flu-like symptoms face long waits to see health care providers licensed to write prescriptions for antiviral medications. Goals and values identified and cited by at least some participants in each location included

- Integrity
  - To encourage civic cooperation and positive community action
  - To foster trust and confidence in the system and in the various players who are making or implementing decisions
  - To prevent panic and negative behaviors such as hoarding

        - While "gaming" the system may occur, it is not a concern unless resources become scarce (see below)
- Safety
    - Accurate diagnosis of flu and other conditions
    - Dispensing of effective, safe, and suitable medicines
    - Maintaining a high standard of care for all
    - Avoiding transmission of flu
    - Educating the public on how to prevent, recognize, and treat the flu, and on the side effects of antiviral medications
- Transparency
    - Trustworthy information provided by government
    - Accurate and consistent communications
    - Concerted outreach to inform vulnerable, isolated populations

A number of additional goals and values were identified by several participants in at least one location. Among them were

- Preparedness (MT, TN)
    - To provide quick access to critical resources
        - Special attention paid to vulnerable groups typically left behind
    - To save the most lives
- Regional equity (MT)
    - In preparedness planning and emergency response
    - Cultural and regional competency

The second discussion scenario, described in Box 2, asked participants to consider what goals and values are most important when not only are delivery systems overwhelmed, but the existing supply of antiviral medications cannot meet demand. The common cross-cutting themes that individual participants cited during this second set of conversations included

- Equity and fairness
    - To ensure equitable access by vulnerable populations (e.g., poor, special needs, uninsured)
    - To prevent favoritism, bias, and discrimination in the distribution of resources both between and within communities

    - To ensure equal access to communications about antiviral treatment
- Integrity
    - Includes compliance with prescribing protocols and priorities
    - To prevent "gaming" of the system, for example, people calling in could learn what answers would guarantee that they got a prescription regardless of whether they had the flu
    - To encourage trust and, thus, public acceptance and cooperation
    - To reduce concerns about favoritism or bias by health care providers
- Prioritize allocation of antivirals[10]
    - To groups identified as high risk for complications or death from the flu
    - To children
    - To pregnant women
    - To the elderly
    - To medical responders
    - To workers who keep society running
    - To vulnerable groups or individuals with a special condition or need who are not designated as high risk, but require special consideration
- Transparency
    - Accurate, consistent information sharing by authorities to maintain public trust and prevent panic and unrest

Goals and values in a time of scarcity that were important to several participants at one or more locations included

- Preparedness (CA, MT)
    - Stockpile antiviral medications to minimize (or eliminate) the need to ration
    - Ensure that antivirals are safe and effective
    - Promote community education and activism
- Prevention (CA, TN)

[10]Although there was general support for the concept of prioritizing anyone identified as high risk, there was little discussion and certainly no consensus about if or in what order any of the identified groups should receive priority.

- Promote infection control and social distancing (including school and house of worship closings) to minimize spread of disease and ultimately conserve limited resources

Reported goals and values varied somewhat between the two scenarios. When adequacy of the supply of antiviral medications was not at issue, individual participants spent more time considering safety concerns. When scarcity was introduced as a condition, discussions tended to include issues of the equitable or utilitarian prioritization strategies for allocating the limited supply of antivirals. Although transparency was often voiced as an important value in both scenarios, it received even more attention in the context of scarcity across all three sites. However, no matter the scenario, trust was a common theme expressed by several participants in Fort Benton and Chattanooga. These participants described their general trust in the intentions of and the capability of nurses, pharmacists, and physicians to perform their jobs. Some participants in Los Angeles, alternatively, were more skeptical of the health care system to provide care equitably and efficiently during routine operations, and expressed heightened feelings of mistrust in their institutions during emergencies.

Nurse Triage Lines

Using NTLs as an alternative strategy for increasing access to prescriptions for antivirals during a pandemic received the most extensive focus at the community conversations. Participants were introduced to the concept of NTLs through several statements in the ARS presurvey, and again in the expert slide presentation. The presentation offered a high-level description of NTLs that included the following information:

- NTLs are hotlines that people who are sick with flu-like symptoms could call for advice, to discuss whether an antiviral medication is indicated, and, if so, to receive a prescription that the NTL would transmit to callers' local pharmacies for dispensing.
- NTLs would be staffed by nurses who would be trained to follow a specific protocol and work under the direction of a physician.
- NTLs would be built on existing regional hotline infrastructure (e.g., poison control centers, 2-1-1) and might leverage other hotlines currently operated by health plans, hospitals, and health agencies.

The presurvey statements were designed to prompt participants' consideration of issues such as whether they would "trust" or "feel safe" getting antiviral "prescriptions" without actually having been "seen" by their usual health care provider and who normally would not be in a position to "decide" to prescribe medications. The statements also asked participants to consider whether their level of trust would vary if prescriptions were being issued for "children," or under conditions of scarcity when there are "not enough antivirals for everyone."

During the two small-group scenario discussions (in pandemic conditions, and in pandemic conditions where medication is also scarce), participants were asked to address three sets of questions that pertain specifically to NTLs:

1. What are the pros and cons of NTLs?
   - What might work well, what could go wrong, what are ways to improve this strategy?
2. Would you trust an NTL nurse who works under the direction of a doctor to prescribe antiviral drugs if you could not see your regular health care provider?
   - Would it matter if the nurse was in another state?
3. If there are not enough antivirals to go around, would you trust NTLs staffed by nurses to make sure these drugs get to the people who should receive them?
   - Can you think of other strategies to make the system more trustworthy?

The following sections describe themes of the conversations around each of these three discussion areas.

Advantages and Disadvantages of NTLs

Individual participants across all three sessions recognized several advantages of NTLs as a strategy for getting antivirals to the public during a pandemic when doctors' offices, clinics, and hospital emergency departments are overcrowded with both the sick and the worried well seeking prescriptions and other treatment. Although participants were not asked to consider shortages of antivirals initially, some seemed to anticipate those circumstances. Common advantages identified by individuals at all three locations included that NTLs could

- offer *convenient, quick*, and *easy* access for most individuals;
- promote social distancing by allowing sick people to access treatment while staying home, thereby helping to contain the spread of disease;
- relieve pressure on other health care providers who are critical to the response; and
- improve access to resources for vulnerable groups (e.g., elders, people with disabilities).

In addition, the following two potential benefits of NTLs were suggested in at least one location:

- Nurses are trustworthy and well trained (CA).
- NTLs could serve as a good source of information and advice about the pandemic and about diagnosing and treating the flu in general (CA, MT).

Despite these advantages, individuals in several small-group discussions at all three locations also raised concerns about the efficacy, safety, and general acceptability of NTLs under pandemic conditions. Specific concerns commonly suggested were

- In a severe pandemic, NTLs could become overwhelmed by the volume of callers, leading to busy signals, long waits, and frustration for callers.
- NTLs omit the face-to-face experience of seeing a provider, increasing the potential for misdiagnosis of the flu or other conditions.
- Some groups would find NTLs difficult to access and navigate (e.g., people without phones, the very sick, elders).
- NTL nurses may not have access to callers' medical histories.
- The technology required may not function during power outages.

Several disadvantages were identified by some participants in at least one location, and included

- NTL nurses are not local, so will not "speak their language" or understand local conditions (MT).

- Callers might lie about their symptoms in order to hoard antivirals for themselves or family members, or sell them on the black market (CA, TN).

Yet beyond the identification of the general advantages and disadvantages of NTLs, individual participants had many suggestions for maximizing the value of NTLs, including

- NTLs must be adequately staffed to prevent long waits.
- The prescribing protocols must be clear, and NTL nurses must be well trained to follow them.
- NTLs should be designed to provide easy, quick navigation to a live operator.
- Planners should develop verification systems to confirm callers' identities and their need for antivirals.
- People should be allowed to call an NTL on behalf of a friend, neighbor, or family member who is too sick or otherwise incapacitated to access the NTL.
- NTLs should establish a mechanism for assessing callers' electronic medical records.

Trust in NTL Nurses

Many participants expressed strong confidence in the abilities and trustworthiness of specially trained, supervised nurses to prescribe antiviral drugs through an NTL if they could not be seen by their regular health care providers. For example, individual participants at all three public engagement workshops highlighted that

- Nurses are well trained and knowledgeable.
- Nurses are trustworthy.
- There is likely a preference for NTLs to be locally staffed and operated.
- NTLs are an acceptable alternative under the difficult circumstances of a pandemic in which normal prescribing channels will not be adequate.

Nevertheless, several participants voiced concerns about the potential for misdiagnosis and misinformation. The issue was framed not in terms of the trustworthiness or abilities of nurses, but in terms of the lim-

itations under which they would have to operate, specifically, lack of face-to-face contact and access to callers' medical records.

The ARS pre- and postsurveys contained two statements pertaining to participant trust in NTL nurses to prescribe antivirals: (1) that they would "trust" NTL nurses to decide if they needed an antiviral prescription; and (2) that they would "feel safe" taking an antiviral prescribed by an NTL nurse. Responses to these questions demonstrated what was heard from several participants during small-group discussions across the three sites: When the circumstances of a pandemic warrant it, NTL nurses can carry out their role to improve access to antiviral medication. Many participants continued to voice that same confidence after they had received more information about NTLs and had had a chance for discussion.

When antivirals are in short supply, individual participants expressed varying levels of confidence in the efficacy and trustworthiness of NTLs and their staff. Participants were asked to consider whether they would trust NTLs to direct antivirals to those individuals who should receive them if there were not enough for everyone. They expressed a number of points that highlighted concerns about NTLs, including

- Many NTL callers will lie about their symptoms, call under multiple identities, or otherwise "game" the system in order to acquire scarce antivirals either to protect themselves and their families or to profit by reselling them to people in need.
- NTL nurses will have little ability to assess honesty, verify who has the flu, or enforce any established prescribing priorities.
- Some NTL nurses might show favoritism toward certain groups, or discriminate against others.
- Absent a face-to-face or other reliable verification system, NTLs would be difficult or impossible to manage during times of scarcity.

Other participants raised the following points, demonstrating their trust in NTLs even in circumstances of scarcity:

- Nurses are trustworthy and capable.
- There is no choice but to trust NTLs under extreme circumstances.
- NTLs would still be useful for providing information and treatment advice, if not antiviral prescriptions.

When participants were asked to contribute their own ideas for enhancing the trustworthiness of NTLs when antivirals are scarce, a common theme was the need to develop some kind of face-to-face verification system, as difficult as that might prove. Other ideas were to establish a whistleblower hotline through which the public could report abuse, and to keep NTLs local on the theory that local organizations would know their public and be harder to deceive. Some participants accepted that gaming of NTLs would be unpreventable during times of scarcity.

Antiviral Pick-Up and Delivery by Community Contacts

The second alternative strategy was presented to participants as a policy to encourage family, friends, neighbors, and other community contacts to pick up prescribed antiviral medications from pharmacies and deliver them to people home with influenza. No further details about this policy were offered, other than the suggestion that local community organizations might have a role in this strategy.

Participants were asked to consider:

1. What are the pros and cons of a pick-up and delivery strategy such as this one?
2. What might work well, what could go wrong, what are ways to improve?
3. Would you have any concerns about going to a pharmacy to pick up antiviral drugs during a pandemic?

Advantages and Disadvantages of Community Contact Pick-Up and Delivery

Many participants at the community conversations had generally positive reactions to the strategy of asking family and community contacts to pick up and deliver antiviral medications for the sick. This strategy's advantages are that it could

- be convenient for people sick at home with flu;
- help contain the spread of disease by reducing the need for sick people to congregate in public places like pharmacies;
- lead community members to check in on the sick; and

- result in more helping hands and encourage acts of compassion by enlisting community members in the effort.

Nonetheless, the small-group discussions did describe the disadvantages of having family and community contacts pick up and deliver medications to the sick. Multiple participants at all three locations were particularly concerned that

- The people doing the pick-up and delivery might face increased personal risks, including exposure to flu, security issues, and legal liability.
- Some family, friends, and community contacts might be unreliable or dishonest; they might keep the antivirals for their own use or resell them for profit, particularly in times of scarcity.
- Some sick people do not have family or community contacts who are willing and able to help.
- Sick people would not see a pharmacist themselves, so would be less likely to receive advice and instruction on the use of their antiviral medications.

Some participants in Fort Benton, MT, also identified the possibility that inclement weather could interfere significantly with this strategy.

Along with this discussion of the strategy's advantages and disadvantages, individual participants contributed a variety of ideas to more effectively implement this strategy, including

- In addition to family and friends, pick-up and delivery of prescribed antivirals could be organized through a network of established community groups and trusted agents.
- Include clear, printed instructions about antiviral treatment for sick people who will not have the benefit of face-to-face consultations with pharmacists.
- Provide personal protective equipment to those who make deliveries.
- Set up dispensing points other than pharmacies to avoid inundating pharmacies.
- Encourage primary and secondary schools and long-term care facilities to file "standing" permission slips that identify persons authorized to pick up and deliver antivirals on behalf of individual students and elders.

Several participants in Montana articulated knowledge of the local conditions as particularly important to making this strategy successful, and therefore, identified community organizations particularly familiar with the local territory—including rural ambulance crews, rural mail service, road crews, and police and fire fighters—that could pick up and deliver antiviral medications as part of their daily job. Many participants in California and Tennessee identified the need for a system to systematically verify and record the identities of those making deliveries, and ensure they had permission from sick individuals to pick up their medication.

The ARS pre- and postsurveys asked participants to state their level of agreement or disagreement as to whether "friends and neighbors should be asked to pick up and deliver prescribed antiviral drugs" from pharmacies for people at home with flu. The responses are consistent with the general support for this strategy expressed during the small-group scenario discussions.

Concerns About Visiting a Pharmacy During a Pandemic

Individual participants identified several concerns they would have about going to pharmacies to pick up prescriptions for family, neighbors, and others sick at home with flu. A common concern was the potentially increased risk of catching flu because pharmacies might be crowded with sick people. Similarly, several participants in each location identified additional concerns, including

- Crowded pharmacies could lead to panic and chaos, raising security and personal safety concerns—especially if antivirals are in short supply (CA, TN).
- People who live in rural small towns could face very long drives to reach a pharmacy (MT).

These concerns were reiterated during the discussions on a strategy to allow pharmacists to prescribe antivirals under collaborative practice agreements with physicians, described next.

Collaborative Practice Agreements Between Pharmacies and Physicians

The third alternative strategy participants considered was allowing people sick with flu to visit a pharmacy for a face-to-face visit with a pharmacist working under a collaborative practice agreement with a physician. Such a pharmacist would be authorized to prescribe and dispense antiviral medications by following specific prescribing "guidelines" or protocols that would be developed by "flu experts" for this purpose. To introduce participants to this idea, the ARS presurvey statements prompted them to think about whether this arrangement should be "allowed" and whether they could "trust" pharmacists to fulfill this role.

During the small-group scenario discussions that followed, participants were asked to address several questions that pertain directly to the strategy of pharmacists prescribing antivirals under collaborative practice agreement:

1. What are the pros and cons of pharmacist prescribing of antiviral medications?
   - What might work well, what could go wrong, what are ways to improve this strategy?
2. Would you trust a pharmacist working under a collaborative practice agreement to prescribe antivirals if you could not see your regular health care provider?
3. Would you have any concerns about going to a pharmacy to pick up antiviral drugs during an emergency?

Advantages and Disadvantages of Antiviral Prescribing by Pharmacists Under Collaborative Practice Agreements

One advantage expressed by several participants was that the public is already familiar with the concept of expanded scope of practice by pharmacists who, for instance, provide flu shots in many locations. Other themes that many participants in small groups in each location identified are

- Pharmacists are knowledgeable and have the best training of any medical professional on antivirals and other medications.
- Pharmacists are trusted medical professionals.

- Face-to-face strategies like this one benefit the sick by offering reliable assessment and diagnosis and by creating an opportunity for a health care professional to advise people on their treatment and answer other questions.
- This strategy offers convenient, "one-stop shopping" for diagnosis and antiviral medication, if indicated.
- Enlisting pharmacists in the response increases the capacity of the health care system.

Many participants across the three workshops expressed a high level of regard for the pharmacist profession. They indicated they would have few reservations about relying on pharmacists to carry out the proposed antiviral prescribing role because they believe local pharmacists are trustworthy and knowledgeable about prescription drugs. Several participants in at least one location also attributed their trust to the following ideas:

- Collaborative practice agreements offer adequate supervision of pharmacists (CA).
- Local pharmacists can be held accountable (CA).
- The local pharmacist is well known and trusted by the community (MT).

Although many participants in all three locations expressed a high level of trust in pharmacists, several common themes emerged when they were asked to consider the potential disadvantages associated with this strategy. In addition to the concerns about visiting a pharmacy during a pandemic to pick up medication for friends and family, several commonly described disadvantages to this collaborative practice agreement strategy include

- Pharmacist prescribing might promote contact between healthy and sick people at the pharmacy, thereby spreading disease.
- Pharmacists themselves might have increased exposure to flu and fall ill.
- Pharmacies could be overwhelmed by masses of people seeking antivirals; other critical pharmacy functions might be obstructed.

Several more disadvantages were noted at one or more of the workshops, including

- Rural areas have few pharmacies and they are far from each other, sometimes requiring long-distance travel (MT).
- Pharmacists probably will not have access to most customer medical records (CA, TN).
- Physicians involved in collaborative practice agreements might not actually follow through on their supervisory responsibilities (CA).
- Pharmacists may have an incentive to overprescribe antiviral medications if they earn a profit from these prescription drug sales (CA).
- Some people might be too sick to leave home to travel to a pharmacy (CA).
- Clarification is needed about whether law enforcement agencies might gain access to pharmacy records (CA).

However, also during the small-group scenario discussions, individual participants identified a number of strategies that could be used to overcome the disadvantages mentioned above, improving the effectiveness and efficiency of pharmacist prescribing through collaborative practice agreements. Strategies included

- Prevent the spread of disease through measures such as providing personal protective equipment to pharmacy staff and customers, and separating the healthy from the sick through use of
  - drive-throughs,
  - points of dispensing, or
  - segregated areas within pharmacies.
- Provide clear, consistent antiviral prescribing protocols and train pharmacists on their use.
- Extend pharmacy staffing capacity by enlisting the help of retired pharmacists, nurses, and other medical professionals (specifically mentioned in MT and CA).

The ARS survey responses in all three locations reinforce the qualitative information gathered from the scenario discussions just described.

Strategies to Inform the Public About Pandemic Flu and Treatment with Antiviral Medications

In addition to the three alternative strategies for prescribing and dispensing antivirals, participants were asked to consider two strategies that would use information technology to convey information to the public about pandemic flu prevention, symptoms, and treatment. The first of these strategies is a web site to provide information about pandemic flu, including prevention and treatment. The second strategy is a text-messaging tool targeted toward people who have been prescribed antiviral medications.

Pandemic Flu Web Site

Participant views were solicited about a web site that would offer self-assessment tools and information about prevention and treatment of pandemic flu, specifically:

- Would you ever use a web site [designed to help people] figure out if they might have flu, or whether they are sick enough that they should see a doctor or go to the emergency room?
- What kinds of information would you want to be able to find on a web site—or not?
- Would the sponsor of the web site matter to you (government vs. private organization)?

Many participants responded affirmatively to the question of whether they would ever use a web site to access information about pandemic flu and treatment options, although some participants noted the potential limitations of web sites for the purposes of self-assessment. Among the commonly described advantages of being able to receive information from a web site were that the Internet is widely accessible, and web sites can offer detailed and up-to-date information about flu and treatment options.

However, throughout the discussion several participants also identified potential disadvantages of relying on a web site for information, including

- Internet service is unavailable in some areas.
- Some populations are less likely to use computers or the Internet, so they may be unable to access this information.
- The reliability of web site content can be difficult to determine.

In Tennessee and California, several participants discussed whether members of the general public, lacking specialized medical training, could accurately self-assess their symptoms. Similarly, small-group discussions in California further expressed the concern that sick people who access the Internet through public portals (e.g., in libraries) could spread the virus.

One issue that emerged from web site discussions was whether a web site should include public forums or blogs. Some participants in Fort Benton and Los Angeles expressed a preference for such tools, while some participants in Chattanooga believed that forums and blogs were a dangerous source of misinformation and fear-mongering. Nonetheless, despite that potential, individual participants in several small groups were able to identify several categories of information they might find most helpful:

- Flu symptoms
- Flu treatment options
- When to see a health care provider
- Information about antiviral medications
  - Where and how to obtain them
  - Side effects

Other ideas that were described as increasing the effectiveness of a pandemic flu web site included

- The web site should provide a user-friendly tool for self-assessment (i.e., one that is based on a decision tree).
- The web site should use simple language and be easy to navigate.
- The web site should be made easily accessible from smartphones and other handheld devices as well as computers.
- All information contained in the web site should come from trusted sources and be closely reviewed for accuracy.
- The web site should include phone numbers to call and speak with a person for more information.
- The web site should present "the truth—the good, the bad, the ugly."
- The opportunity to communicate directly with a nurse through the web site (e.g., Skype or instant messaging) would be a desirable feature.
- Videos to present information would be useful for all, but especially for people at lower literacy levels.

Not only did participants discuss the content of the web site, but they were asked to discuss whether the sponsor of a pandemic flu web site would matter to them and, if so, whether a government or private sponsor would be preferable. Many participants at all three sessions indicated that the sponsor would be important, and that the sponsor—whoever it is—must be a *reliable* broker of *accurate* information. On the question of whether such a web site should be sponsored by a government or private entity, responses were mixed, with many participants expressing neutrality on the issue. Individual participants who favored a government sponsor cited the following reasons: (1) commercial web sites tend to be promotional and, thus, less trustworthy; (2) government has the requisite expertise and access to information; and (3) government has a duty to protect the public's health, including the role of information disseminator. Several participants who favored a private sponsor noted a general distrust of government.

Finally, notwithstanding the possible barriers and other concerns cited by some, many participants at all three sites thought that, if they had flu-like symptoms, they "would like to be able to go to a trusted web site for advice on whether to seek treatment."

Text-Messaging System

The second information strategy consists of a text-messaging system that would issue a series of messages to people who already have been prescribed antivirals. This strategy was presented in general terms as a way for people to opt in to receive text messages from "the experts" that could help them manage their antiviral treatment.

Participants were asked to consider "a system that would send text messages to cell phones of people who have been prescribed antiviral drugs—at their request—to remind them to take their drugs, to advise them of possible side effects, or to provide other information about their flu treatment." Individual participants who favored this strategy listed the following advantages in favor of it:

- Text messaging would be a convenient source of additional information.
- Such a service would be particularly popular among younger people.
- Cell coverage is stronger and more complete for texting than it is for calling.

- Text messages would provide a record of information to which recipients could refer back.
- Reminders to take the antivirals were perceived by many as a good idea.

However, other participants expressed some concerns, such as:

- Text messaging is not accessible to all.
  - The elderly tend not to text.
  - Some people do not own cell phones.
- Frequent text messages cause people to disregard them.
- A high volume of text messages could overload the phone system.
- Cell coverage is poor in certain locations and in bad weather (MT).
- Text messaging would be unaffordable to some, unless the service is provided free of charge (CA).

Several participants offered other suggestions for maximizing the value of phone-based tools. One example is the importance of ensuring that the sender of the text messages is a reliable, neutral source. Another suggestion is to offer e-mails as well. Other participant ideas included (1) weaving in positive, reinforcing messages to support sick people's emotional well-being; (2) providing an option to "stop" receiving text messages; and (3) offering text messaging as a free service.

The positive response of many participants at each site to the concept of an opt-in text-messaging system is reinforced by the ARS survey responses, in which many participants indicated they would like the option to receive text messages about the flu and the antiviral medications they were prescribed.

When Antiviral Medications Are in Short Supply

The second scenario added the complicating factor of scarcity: now, participants were told, not only are the normal channels for getting prescriptions for and acquiring antiviral medications congested, but there is not enough antiviral medication for everyone. Participants were asked to consider four questions related to scarcity:

1. If there is a shortage, do you agree with the policy to limit antiviral drugs to people at highest risk for serious problems or death?
   - Are there other preferred policies for allocating scarce antivirals?
2. Should all health care providers follow the same rules when deciding who should receive this limited supply of drugs?
   - If so, are there some circumstances when individual health care providers should be allowed to make decisions that go against the rules?
3. When there are not enough antivirals to go around, would you trust NTLs to get these drugs to the people who should receive them?
4. When there is a shortage of antiviral drugs, what are the most important values and goals?

Policies for Allocating Scarce Antiviral Medications

Participants discussed whether, if antiviral medications are in short supply, the policy should be to limit distribution to members of groups identified as at high risk for complications or death. Participants also were asked to consider whether they would prefer an alternative allocation scheme such as "first come, first served" or a lottery. No additional information was presented to participants about how these different strategies could be implemented or about the trade-offs that each would entail.

Many participants at all three sites strongly supported the concept of directing scarce resources to people in greatest need who would benefit the most. Most of the reservations about this approach were expressed as a desire to create exemptions or exceptions to the rule for certain groups or under certain circumstances rather than a wholesale rejection of the idea. Several themes of the discussion across the three locations included that:

- Allocating scarce antivirals to people in high-risk groups:
  - Will save the most lives
  - Is equitable if applied consistently
  - Otherwise, people of means will have an unfair advantage in accessing treatment
- Trust in judgment of medical experts about high-risk designations is necessary and warranted

- Some groups—in addition to the high risk—should always receive priority:
  - Ideas varied ideas about which groups should qualify for this priority status (e.g., children, pregnant women, medical responders, elders)
- Anyone who is truly sick should be eligible to receive antivirals (CA, TN)

Some discussion in at least one location considered on other aspects of the issue of how to dispense antiviral medication in an atmosphere of scarcity, citing the idea that:

- People in high-risk groups should only receive scarce antivirals if they are likely to benefit (CA, TN).
- Determinations as to which populations are at high risk must be reliable (CA, MT).
- Local authorities should have a say in determining antiviral allocation, after taking into account CDC or state guidelines (CA, MT).
- Exceptions should be made for people with special medical conditions who are not within the identified high-risk groups (e.g., immunosuppressed, asthmatic) (CA).
- Incarcerated and institutionalized populations should not be excluded or disadvantaged by any allocation strategy (CA).

Several small-group discussions at all three community conversations recognized the merit of "first come, first served" and lotteries, but generally disfavored both of these allocation strategies. Lotteries were regarded by some as fair given their relative randomness and lower risk of discrimination against the powerless. But more participants saw lotteries as logistically difficult, potentially chaotic, and subject to gaming. Some also noted that, because randomizing distribution ignores potential risks and benefits, lotteries also are likely to waste scarce resources on people who do not need them. "First come, first served" was even less well regarded as an allocation strategy by many. Although some participants asserted that "first come, first served" might be fair in the sense that it removes third parties from the decision-making process, many participants were concerned that it would put certain populations at an unfair disadvantage while favoring those with the circumstances or means to access the system quickly and to their benefit.

Despite the general disapproval of "first come, first served" and lotteries, some participants suggested that these allocation approaches could be useful for distributing any remaining supply of medications once the high-risk groups have been treated or for allocating within a high-risk group if the supply of antivirals is so limited that it will not cover even that entire group.

The ARS survey responses for each session indicated a trend of support for allocating scarce antivirals to "people who need them the most," consistent with the relative weight of individual participant views reported from the scenario discussions.

Provider Uniformity or Flexibility When Prescribing Scarce Antiviral Medications

The final question addressed by participants was whether all health care providers should follow the same rules when deciding who should receive scarce antiviral medications. Individual participants who agreed with this proposition also were asked to consider whether there are some circumstances under which individual health care providers should be allowed to make prescribing decisions that deviate from the rules. On the preliminary question, several strong themes emerged, including

- Consistency in decision making is essential for reasons of equity and promoting trust in the system.
- Provider adherence to guidelines is likely to result in more antiviral medications going to people who need them the most.
- Use of uniform prescribing guidelines is the most fair approach because the guidelines help prevent:
  - Discrimination
  - Favoritism by providers who have established patient relationships
  - Certain wealthy, powerful individuals from buying access
- The CDC and other health agencies can be trusted to use their expertise to set appropriate guidelines.

The question of whether it would ever be acceptable for providers to "go against the rules" elicited mixed reactions. Many participants asserted that allowing any flexibility would lead to too many exceptions and, in turn, unfair allocation decisions. Others believed that some flexibility in providers' exercise of their professional judgment would be advanta-

geous. Those in favor of flexibility recommended instituting controls such as guidelines that define when such flexibility would be warranted. Such guidelines should also clarify that exceptions to the rules are rare and must be based on reliable information about a patient's condition rather than bias for or against certain individuals or groups. Other common suggestions were that providers should have the discretion to prescribe antivirals to people who are truly in need, or on the margins of a high-priority category (e.g., a 59-year-old if the cut-off were age 60 and above).

Several participants conveyed unsolicited thoughts about enforcement of prescribing guidelines during times of scarcity. Suggestions included creating a hotline or other system through which providers and the general public could report noncompliance, and establishing and enforcing sanctions against providers who break the rules.

Individual Participants' Ideas for Prescribing and Dispensing Antiviral Medications in a Flu Pandemic

At various points throughout the community conversations, participants were encouraged to contribute their own ideas about other strategies for getting antivirals to the public quickly, safely, and fairly. Individual participants offered numerous suggestions that fell roughly into three categories—dispensing, communications and outreach, and preparedness planning.

Dispensing

Common themes discussed by several participants at each location related to expanding human resource capacity by recruiting workers and community members who normally would not play roles in the delivery of antiviral medications; using a variety of community settings as alternative distribution centers; and repurposing mobile resources to deliver antivirals to people in the community. Themes included

- using schools, libraries, post offices, senior centers, and places of worship as dispensing centers to increase convenience and relieve pressure on pharmacies;
- setting up drive-throughs at pharmacies to provide face-to-face contact with pharmacists while facilitating social distancing to prevent the spread of disease;

- setting up points of dispensing in key locations; and
- tapping into existing networks of community and government organizations to deliver antivirals to people who are sick at home.

Several participants in Fort Benton indicated that they would trust veterinarians to prescribe antiviral medications in order to expand prescribing capacity. Two minor themes raised at the Los Angeles session were (1) the need to regulate the distribution of antivirals to pharmacies so that every local community receives its fair share; and (2) the creation of a system through which people could return unused antiviral medications for distribution during times of shortages.

Communications and Outreach

Many participants at each location identified the importance of employing a wide assortment of communications tools—traditional media (e.g., television, radio, direct mail, billboards), new media (e.g., Twitter, Facebook), and Public Alert Networks (e.g., Reverse 9-1-1)—to push information about the pandemic and antiviral treatments out to the public. The use of varied communications tools was considered by many to be the most effective at reaching diverse audiences.

Other participants suggested deploying EMTs (emergency medical technicians) and other health care professionals to conduct information sessions in local neighborhood settings, and ensuring that communications will be accessible to people who are deaf or hard of hearing or have impaired vision. An idea from the Los Angeles session was to recruit celebrities to star in public service announcements, while many participants in Fort Benton recommended the promotion of word-of-mouth information-sharing strategies like phone trees. A Los Angeles participant also suggested developing a community support network to check on senior citizens to make sure they know how and when to take the antiviral medications that have been prescribed for them.

Preparedness Planning

Numerous participants at each site frequently noted the general need for public education and awareness prior to the onset of a flu pandemic; individual participants in Chattanooga recommended engaging the public in preparedness drills. Several in Los Angeles suggested previewing and

getting buy-in from the community on any proposed dispensing plan through neighborhood councils. Another suggestion was to encourage prior credentialing and training of volunteers who could be deployed to respond to a pandemic.

Additional Participant Comments

At each of the community conversations, ideas emerged that either represented overarching themes for that session or were not directly within the scope of inquiry, but are relevant and worthy of acknowledgment nevertheless.

In Fort Benton, some participants raised the question of why the Food and Drug Administration or other federal agency could not simply approve the over-the-counter sale of antiviral medications during a flu pandemic as a way of resolving the prescribing bottleneck, considering the drugs to be relatively safe. Consistent with repeatedly voiced concerns that rural areas are at a disadvantage to the "big cities" when it comes to prompt allocation of critical resources like antivirals, several participants also questioned why rural public health agencies could not simply stockpile locally. But perhaps the most frequently repeated theme at this session was the high level of trust and cooperation that permeates rural communities, and the sense that Fort Benton would be among the best places to be during a major pandemic.

This theme of trust was also evident in Chattanooga, where the emphasis was on participants' trust in the knowledge and character of health care professionals "to do the right thing" when prescribing and dispensing antivirals during a pandemic. However, some Chattanooga participants did voice worries about the sufficiency of medical stockpiles and concerns about access to treatment by the uninsured.

Many of the Los Angeles participants' references to "trust" were cast differently than at the other two sessions. A general distrust was frequently expressed at this venue, attributed to minority communities' interactions with the health care system. Beyond specific concerns about how and where critical resources would flow during a crisis, several participants—citing the neglect of patient consent in the 1932 Tuskegee syphilis study—shared their belief that minority groups would be used as "human guinea pigs" to test antivirals and vaccines, but would be the last to receive the benefit of these treatments. A few Los Angeles participants also voiced worries about the safety and components of antiviral medications themselves (the risk of "contamination"), and a desire both for al-

ternative holistic remedies and for safeguards to prevent pharmaceutical companies from rushing to market dangerous drugs.

A comment that arose in all three locations was that preparedness planning for pandemic influenza—and other public health emergencies requiring the large availability of medications—should be sufficiently robust that scarcity should never be an issue. Each session included one or more participants who were adamant about this point, some of whom took the time to record comments on index cards or their written evaluation forms. Several participants in Fort Benton and Chattanooga favored a strategy of allowing or encouraging the stockpiling of antivirals at home. A few examples of written comments from the Chattanooga session include

- *"Most important—we should not run out!!! Make sure there are enough meds for everyone."*
- *"If gov't handed out a bottle per family right now, most of these scenarios would never happen."*
- *"If you distribute [the stockpile] now, there's not a possibility of rushing or overcrowding, and no chance of contamination during delivery."*

Participant Evaluations

Finally, participants were asked to share their perceptions about the quality and value of the public engagement process through a series of ARS statements and a brief written form that provided the chance for them to identify the most valuable parts of the session, whether anything was missing, and add any other comments they might have. Participant ARS responses for all three community conversations reflected several common themes:

- The information presented was trustworthy and helped them understand the challenges of getting antivirals to the public in a pandemic.
- The scenario discussions were productive and allowed them to express their views.
- Hearing other participants' opinions was useful.
- By the time they took the postsurvey, they had a better understanding of the issues.

- They would recommend that family and friends participate in a similar session if offered the chance.

On their written evaluations, many participants in all three workshops reported that they felt well informed about the issues which they were asked to discuss, and that the agenda and materials gave them adequate opportunity to have meaningful discussion and express their ideas.

DISCUSSION

Few significant regional differences emerged across the community conversations. Individual participant commentary from all three sessions indicated widespread support for the overarching concept that public health authorities should develop alternative strategies to help people gain access to antiviral medications during an influenza pandemic. As noted above, many participants also expressed broad acceptance of all of the specific prescribing and dispensing strategies presented, as well as for the web site and text-messaging tools aimed at enhancing public access to information and advice about pandemic flu and treatment with antiviral medications.

Many participants also acknowledged the advantage of a "layered" approach to facilitating access to antivirals (i.e., the need to employ multiple strategies to reach different groups and respond to different circumstances). Qualitative information from several small-group discussions underlined the understanding that no single strategy could satisfy all needs at once; even when some participants voiced criticism of individual strategies on the basis of identified limitations, they still regarded them as generally acceptable. Several participants across the three sites did express reservations about the application of certain proposed strategies in the context of children (i.e., perceived safety issues), and when antivirals are in short supply (i.e., concerns about dishonesty and unpreventable "gaming" of the system). Alternative prescribing and delivery strategies will have to account for these concerns in order to receive the public's trust and acceptance when implemented in a pandemic. Finally, public trust and acceptance also will depend on continued education to

build public awareness and understanding of these or other alternative strategies.[11]

FINAL REMARKS

These community conversations on alternative strategies for facilitating access to antiviral medications during an influenza pandemic represent a novel initiative by the IOM to engage the public in public health preparedness planning at the national level. As intended, the three sessions convened members of diverse regions and populations for vigorous discussion of the acceptability of alternative delivery and informational strategies for antivirals presently under development at the CDC. Although the outputs generated by these public engagements do not represent a consensus and are not generalizable to wider populations, they do describe a variety of attitudes, concerns, and potential areas of misunderstanding that the CDC could expect to encounter in its future planning activities or when implementing any of these strategies during a pandemic. Similarly, they include potentially useful suggestions for improving or building on the current proposed strategies.

Finally, the purpose of these community conversations was not to test the general value of public engagement in the development of public health strategies. However, the depth, breadth, and quality of the information yielded by the discussions, the apparent increase in participant understanding and acceptance of the proposed strategies, and the positive responses reflected in evaluations all suggest that these types of forums offer reciprocal benefits to participants and policy makers and have a great potential to positively impact the development of public health policy.

[11]One observation, common throughout the community conversations, was the tendency of many participants to refer to antiviral medications and vaccines interchangeably. Whether misunderstandings relate to differences between medications and vaccines or differences among antivirals (i.e., to treat people with influenza or HIV), policy makers should not assume that everyone is knowledgeable about the distinctions.

Appendix

Recruitment Flyer

Participant recruitment was primarily the responsibility of the local organizations with whom the Institute of Medicine planning committee partnered.[1] As part of the development of the workshop materials, the planning committee provided each local partner with the flyer below to use as a foundation for its individual recruitment efforts in order to standardize certain common recruitment messages. Each local partner then adapted the basic flyer using its respective location and logistical details.

[1]The following is a list of the local partners by workshop location—Fort Benton, Montana: Montana State University, Choteau County Extension, Chouteau County Public Health; Chattanooga, Tennessee: Chattanooga-Hamilton County Health Department; Los Angeles, California: Healthy African American Families II, Department of Public Health–Los Angeles County.

IN A **FLU PANDEMIC**,
HOW COULD WE GET
LIFE-SAVING MEDICINES TO THE PUBLIC?

Your Voice Matters!

What are the best ways to make sure that people have quick, safe, and fair access to antiviral drugs if a flu pandemic were to strike? Public health agencies are planning to respond. Please join a Community Conversation to ***share your ideas about possible new strategies***.

WHO: General public ages 18 or older (must be comfortable speaking English)
WHEN: [Date and time]
WHERE: [City] (details upon registration)

Participants will receive a $50 stipend
Lunch and refreshments will be served

You Must Preregister!!
For more information, please call [name] at [number] or e-mail [address]

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OF THE NATIONAL ACADEMIES

in collaboration with [Local partner logo]