



Public Engagement Project on
**Medical Service Prioritization
During an Influenza Pandemic**

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Executive Summary

A severe influenza pandemic will have profound impact on the health care delivery system. Shortages of life-sustaining medical resources, including hospital beds, trained health care providers, intensive care unit resources, medical supplies, equipment, and medications, are expected. Rationing of scarce resources and alterations in the standards of health care delivery are widely acknowledged to be necessary components of the response to large scale health emergencies; yet, there has been little public dialogue on these issues and detailed guidelines are not yet available.

To address these gaps, Public Health - Seattle & King County (PHSKC) engaged the public to better understand their values and priorities regarding the delivery of medical services and how those services will be allocated during a severe pandemic influenza. The public engagement process is critical to help ensure the incorporation of the community's values and priorities into the policies, plans, and guidelines that PHSKC develop for the region.

The engagement process included input from a total of 153 participants in four public engagement forums drawn from diverse citizens in the community and vested stakeholders¹ (Appendix A - Stakeholder Participation). The meetings were designed to allow individuals to think through the difficult decisions that need to be made by medical professionals during a disaster in an interactive format. They discussed the priorities for the rationing of scarce resources among peers and provided recommendations and insight on how those decisions should be made. The format was a combination of individual survey, small group discussion and large plenary discussion — allowing for participants to inform each other's opinions over the course of the meeting. An evaluation of the project was completed by the independent University of Nebraska Public Policy Center and included a survey distributed to all participants before and after each forum (Appendix B - Survey Evaluation Results). The process was guided by a steering committee representing medical services and care providers, health care experts, and emergency responders from state and local government, academia, and community-based organizations (Appendix C - Steering Committee Members).

In summary, several common themes emerged from the engagement forums.² The following section summarizes highlights.

¹ Stakeholders with vested interest include, for example, health care providers, emergency workers and community advocates.

² Meeting summaries from each of the forums are included in Appendices D - G.

1. How should decisions be made about rationing of limited, life-saving resources and what are the goals?

Much of the meetings' discussion was about how to prioritize groups of people for medical treatment. There was overall support among meeting participants concerning the importance of *survivability* as a treatment prioritization criterion. The goal expressed was to *treat as many people as possible* even if that results in lowered standards of care. There was mixed response among the citizen and stakeholder participants on whether hospitals should take into account *the number of years* a person would live if they survived and if younger people should get treatment priority over older people. After significant deliberation, the majority of participants agreed that the number of years a person would live if they survive (also discussed in terms of the age of the patient) should only be a factor in the absence of any other priority criteria. Overall, participants reflected a high degree of faith and trust in medical caregivers (doctors and nurses in particular) to make appropriate determinations based on their expert opinion about survivability.

The question of prioritizing people for treatment according to their *role in society* was met with mixed reactions. Many participants were supportive of doctors, nurses, and first responders receiving prioritization because they can help support the health care infrastructure that provides treatment to the greatest number possible. There was also discussion, however, about the need for many different roles in society. Participants began to shy away from supporting a system that would prioritize treatment based solely on the role that one played in society. The issue of *equity* became more strongly supported than determinations based on role.

2. What decision criteria are least important or off limits?

All participants agreed that decisions using criteria that discriminates according to race, gender, culture, legal status, nationality, or language are not acceptable. Participants also strongly expressed that the ability to pay was among the least important considerations. Alternatively, a person should not receive preferential treatment based on their ability to pay.

Participants overwhelmingly rejected "first come, first served" as a basis for determining access to scarce, life-sustaining medical resources. They also felt that random selection should not be used because it would not ensure the best use of resources.

3. Should decisions about medical treatment be consistent?

Across all forums, the participants raised the need to establish standards or guidelines that health care facilities could follow consistently across the state to allocate medical resources.

4. Other Prioritization Factors

Other prioritization issues were discussed, including:

- The prioritization system should be relatively simple to support successful implementation and administration, and not overly influenced by emotional decision making during a time of crisis.
- Decisions should be made based on expert opinions about medical condition and survivability, and a prioritization system should be based on fair and equal access.
- Groups discussed giving priority to health care workers as a means of best serving the needs of society in a time of medical crisis.

Background

The year-long *Public Engagement Project on Medical Service Prioritization During an Influenza Pandemic* began in September 2008 and was supported by a grant from the Centers for Disease Control and Prevention (CDC). The project was designed and implemented to better understand the public's values and priorities regarding the delivery of medical services during a severe pandemic influenza, including priorities for access to limited life-sustaining medical resources.

A. Statement of Need

Both moderate and severe influenza pandemics will have profound impacts on the health care delivery system. Using CDC's modeling software, a Severity Index 5 pandemic influenza event estimates a 30% gross attack rate with a case fatality ratio of at least 2%. King County has a total population of 1.8 million of which approximately 400,000 are children aged 0-18 years old. Thus, over a theoretical eight-week time span of a Severity Index 5 pandemic, we estimate that 540,000 King County adults would be ill of which 11,418 would die. It would result in the need for approximately 60,000 hospital beds during the course of the epidemic, and approximately 270,000 excess outpatient medical visits. Demand for medical beds would require approximately 40% of available beds in a moderate pandemic and over 250% of available beds in a severe pandemic. Demand for intensive care unit resources would exceed capacity in both scenarios. In addition, shortages of material resources including medications, medical supplies and equipment, and of trained health care providers are expected.

Rationing of scarce resources and alterations in the standards of health care delivery are widely acknowledged to be necessary components of the response to large-scale health emergencies. Among all the medical services provided in a community, it is likely that many will need to be either severely curtailed or temporarily suspended during a severe pandemic. Currently there is no national or regional consensus regarding a standard approach to triage of patients, or implementation of altered standards of medical care during a disaster. Despite the significant impact on the community, to date, there has been little public dialogue on these issues, and no sufficiently detailed guidelines have yet emerged from professional organizations. Input from the public is needed both to help determine which health and medical services should be prioritized, and how these services will be allocated among ill persons when the demand exceeds the available capacity.

B. Steering Committee

To advise them in the process, the project staff convened an advisory committee representing medical services and care providers, health care experts, community advocates and emergency responders from state and local government, academia, and community-based organizations that are responsible for recommending and implementing public health policy and programs for all people throughout the region (Appendix C- Steering Committee Members). The committee helped identify the goals, design the process, recruit participants to the forums, and provide input to and review of the final report.

C. Project Goals

The opinions of the general public and stakeholders on this issue are a valuable part of the policy and decision-making process. The decisions will impact the public directly and they will need to contribute innovative thinking, practical solutions, and implementation support to the challenges that will be faced. Broad participation contributes to sound, sustainable and widely supported public health management policies and practices. The results of the project will be incorporated into the regional pandemic flu planning activities and help to inform policies in the region's Pandemic Flu Plan.

The public engagement project's goals were to:

1. Obtain feedback and recommendations from the community regarding the prioritization of medical services during a severe pandemic, and how those services will be allocated.
2. Explicitly define the community's values underlying the above recommendations.
3. Ensure the incorporation of community values and priorities into regional planning for delivery of health and medical services during a severe pandemic.

Based on the input from the steering committee, the framing questions used during the engagement process to focus the engagement with the public included:

1. Should we change how medical treatment decisions are made during an influenza pandemic?
2. What should the goal(s) be when decisions are made about medical treatment during an influenza pandemic?
3. How should decisions be made about rationing of limited, life-saving resources?
4. Should decisions about medical treatment be consistent?

Methods

PHSKC convened four community engagement meetings to better understand the public's values and priorities regarding the delivery of medical services and how those services will be allocated during a severe pandemic influenza. The meetings brought together participants from the following communities:

- Stakeholders (30 participants; Appendix E)
- Residents in North King County (57 participants; Appendix D)
- Residents in South King County (49 participants; Appendix F)
- Spanish-speaking residents (17 participants; Appendix G)

A. Recruitment and Participant Demographics

Two main publics, residents-at-large who represent no organized or special interests, as well as representatives of interested stakeholder organizations from key affected sectors, were recruited to participate in the public engagement forums. To assist in the recruitment of residents-at-large ("public participants"), PHSKC received input from its steering committee and the Vulnerable Populations Actions Team (VPAT).³ VPAT identified community-based organizations who might serve as partners. In turn, the community-based organizations helped recruit participants, consulted on culturally-appropriate methods, and checked translations of the materials. Additionally, recruitment was conducted through

³ Vulnerable Populations Actions Team (VPAT) was established by PHSKC to ensure access to public health preparedness information, response, and recovery services for the most vulnerable and hardest-to-reach residents in King County.



outreach with schools and volunteer emergency response organizations, parent groups and associations, faith-based organizations, housing organizations, and student organizations. The opportunity for participation was advertised on Craig's List and through flyers posted in community centers, libraries, and other public places located near the sites of the public engagement meetings. Participants were offered \$100 for attending the 8-hour meetings.

Recruitment efforts resulted in a broad range of public participants, based on gender, race, ethnicity, age, income and education. The majority of participants were female, with 70% female, 30% male. Twenty-four percent of the public

participants identified as being of Hispanic origin or ethnic background, reflecting the Spanish-speaking meeting. Almost two-thirds of the participants identified as white, with 11% African American, 7% Asian, 1% Native American, and 19% identifying as "other". The public participants represented a diverse age span (see Table 3, Appendix B), range of education (see Table 2, Appendix B) and household income level (see Table 6, Appendix B). In particular, there was a large number of participants living near the poverty line, with 39% with an annual household income of \$15,000 or less and an additional 17% with an annual income of \$15,001 to \$30,000. This may reflect the clientele of the community partners who assisted with recruitment, and perhaps the relative value of the \$100 incentive given for participation.

At the key stakeholder meeting, participants were recruited from a wide-range of community organizations and agencies, including:

- Hospitals, health care providers, and administration staff including community health clinics, home health care agencies, and nursing and adult living homes
- Emergency response and management
- Businesses
- Faith-based organizations
- Social service and advocacy organizations serving diverse populations, including immigrant and refugee service providers, sensory and physical disability providers, and housing service providers.
- Schools

The stakeholder group was a little more evenly divided between men and women, with 43% male participants and 57% female. Ten percent of stakeholders identified as Hispanic. Seventy-five percent of the stakeholders were white, 15% identified as Black or African American, 5% identified as Asian, and 5% identified as other. The vast majority of stakeholders were between the ages of 45-64.

Stakeholders were largely graduate school graduates, and all stakeholder participants had completed some college. Their income levels were also substantially higher than those in the public participant group, with 62% receiving annual household incomes of over \$100,000 (see Appendix B).

B. Meeting Design

Each public engagement meeting was designed for participants to learn from each other, understand one another's perspectives, and identify common ground on values and priorities. These objectives were achieved through the use of several decision-making and deliberative tools: the Q-Sort methodology, facilitated breakout session discussions of hypothetical health care vignettes, and plenary discussions. The tools helped to illuminate the range of opinions that are held among the participants and to document where common ground existed. All meetings had a professional lead facilitator along with teams of facilitators and note-takers for each breakout group convened during the Q-Sort and vignette discussions. Each breakout group had approximately eight participants.



The Q-Sort methodology was used to address the question: *How should decisions be made about rationing of limited, life-sustaining resources?* The activity was designed to help understand what considerations are most important to the individual participants when it comes to decisions about health care treatment during disasters. Participants sorted 27 opinion statements taken from real opinions given by members of the general public and health care experts. The participants rank-ordered the statements along a continuum from most important to least important. (Appendix H - Q-Sort Methodology).

In each forum, breakout groups were also asked to consider a series of hypothetical scenarios or “vignettes” intended to help participants personalize the kind of decisions that will likely be made in the case of influenza or other severe pandemic. Using a “World Café” style process, participants in the small groups moved through a suite of three vignettes. Each group was asked to build on the discussion of the previous group as part of a progressive conversation that integrated the ideas of all perspectives into a coherent outcome. The vignettes and discussion details from each forum are shown in Appendices D - G. Plenary discussions were also facilitated among the full group to discuss the outcomes from each breakout session, and highlights from these discussions are also included in the appendices.

C. Survey and Evaluation

An independent evaluation of the project was completed by the University of Nebraska Public Policy Center under contract to the CDC. They distributed a pre- and post-meeting survey among all participants. In addition to evaluating the public engagement process, the surveys included questions from project staff asking participants to indicate level of priority for specific groups, their support for standardization of altered standards of care, and the importance given to specific goals for medical service prioritization. University of Nebraska staff also conducted focus groups with participants and interviews with steering committee members to evaluate the project process. The full results are included in Appendix B - Survey Evaluation Results.

Results At-A-Glance

A summary of key outcomes and results from all methods of engagement previously described is included in the following table.

GUIDING QUESTIONS	FINDINGS
Should we change how medical treatment decisions are made during an influenza pandemic?⁴	Yes. Disasters will require implementation of altered decision-making processes and protocols to determine allocation of scarce medical resources.
What should the goal(s) be when decisions are made about medical treatment during an influenza pandemic?⁵	Treat as many people as possible, saving the greatest number of people even if it means that the standard of care must be compromised. Create a prioritization system that is fair and accessible to all people.
How should decisions be made about rationing of limited, life-saving resources?⁶	Saving the greatest number of people should drive decisions. Survivability is a priority treatment consideration to help ensure that scarce resources are used most efficiently for those that will benefit most. Health care providers and first responders are top priorities because they can help respond to the immediate crisis and help make the best use of the resources available to treat the greatest number possible. To a lesser degree, children and pregnant women should receive some priority when all other factors are equal. The ability to pay was among the least important considerations. Guidelines for rationing should ensure that discrimination cannot enter into decisions.
Should decisions about medical treatment be consistent?⁷	Hospitals within a state or hospitals throughout the US should use a consistent system for medical treatment during a pandemic. Guidelines should allow some flexibility to enable facilities to distribute needed resources based on demand and availability.
Withdrawal of life-saving care⁸	Participants generally struggled with idea of withdrawing life-saving care — even if it meant that other lives would be lost. Most people felt that the choice was best made by the patient or patient’s family with input from a doctor or health care provider.

D. Findings

Findings were drawn from qualitative data from documentation of plenary and small group discussions, Q-Sort data, and the pre- and post-surveys. Overall, participants in all groups found the prioritization process for scarce, life-sustaining resources to be very difficult. Nonetheless, they overwhelmingly reflected the opinion that difficult choices need to be made in advance of a severe pandemic in order to ensure a fair, equitable and well-managed system of response.

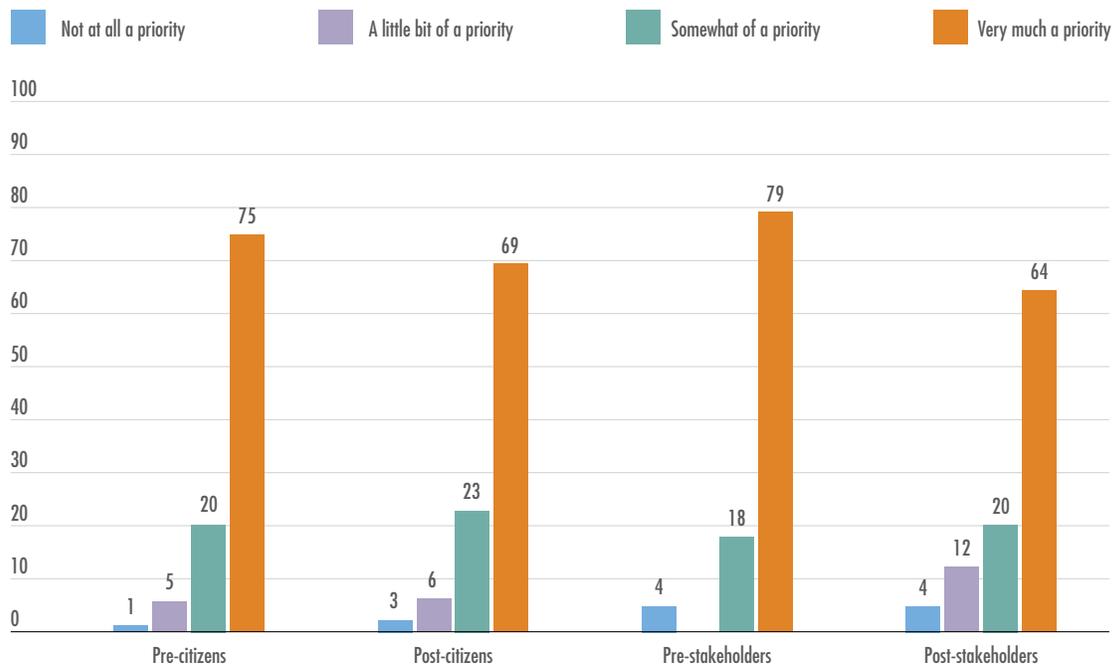
⁴ U. of NE evaluation data and plenary discussions

⁵ Q-Sort data, vignette discussions, plenary discussions, U. of NE evaluation data

⁶ Q-Sort data, vignette discussions, plenary discussions, U. of NE evaluation data

⁷ Q-Sort data, vignette discussions, plenary discussions, U. of NE evaluation data

⁸ Vignette discussions

Table 1. Prioritization of first responders

Goals, Implementation, and Standardization: Similar perspectives among groups

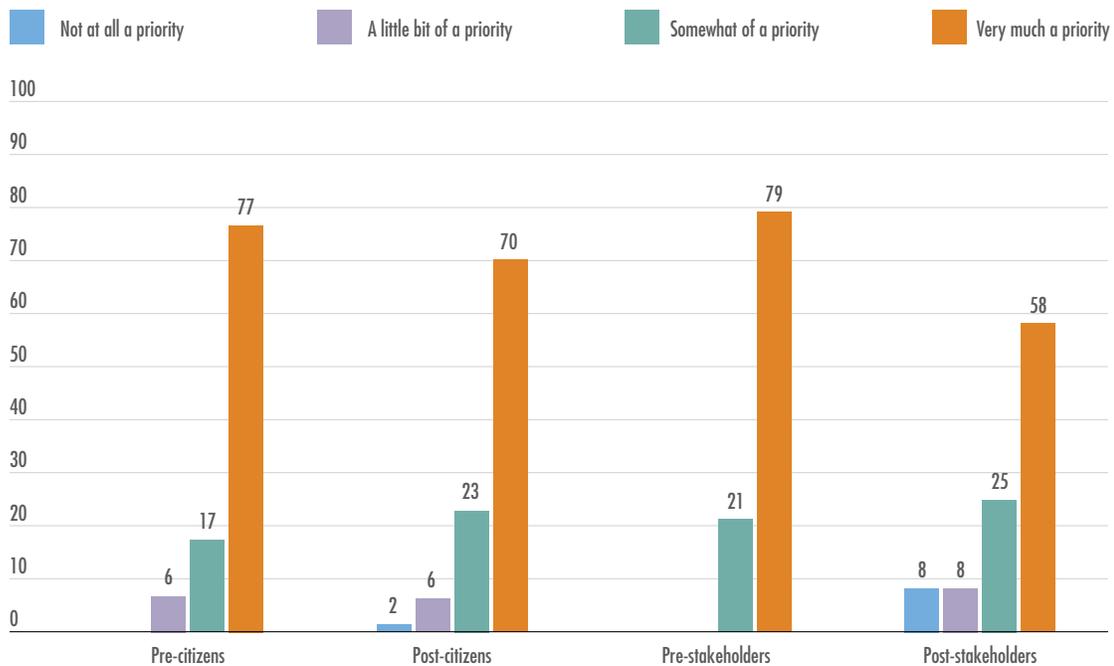
Overall, there was considerable agreement among public participants and key stakeholders regarding the goals of medical service prioritization during disasters and how it should be implemented. A vast majority of participants agreed that *providing treatment to the greatest number of people* was a top goal, even if it resulted in a lowered standard of care. Participants also agreed that *fair and equitable prioritization* of medical services should be a goal.

Survivability was considered by most of the participants to be a decision-making priority, since treating as many people as possible would maximize resources. By the close of the meetings, 85% of the public participants and 96% of the stakeholders agreed that hospitals should take into account patient survivability into allocation of scarce, life-saving medical care. Regardless of how important an individual is based on his or her role in society, expending significant resources on an individual who is not likely to survive, or will survive with a low quality of life, was seen as a sub-optimal use of medical resources. This factor was emphasized in particular at the stakeholders meeting — where survivability was generally emphasized above all others as the most important consideration.

Strategies based on “first come, first served,” randomization, or ability to pay were widely rejected as criteria for deciding which patients would receive scarce, life-saving treatment, as indicated in all plenary sessions and in the University of Nebraska evaluation data (see Appendix B, Tables 18 - 22).

In discussing who should have priority for medical treatment, all the plenary sessions reflected the participants’ struggle with the challenge of assessing an individual’s “value” to society. Significant deliberation focused on this issue. *First responders, doctors and other health care providers* were considered a very high priority for the majority of stakeholders and members of the public alike (see Tables 1 & 2).

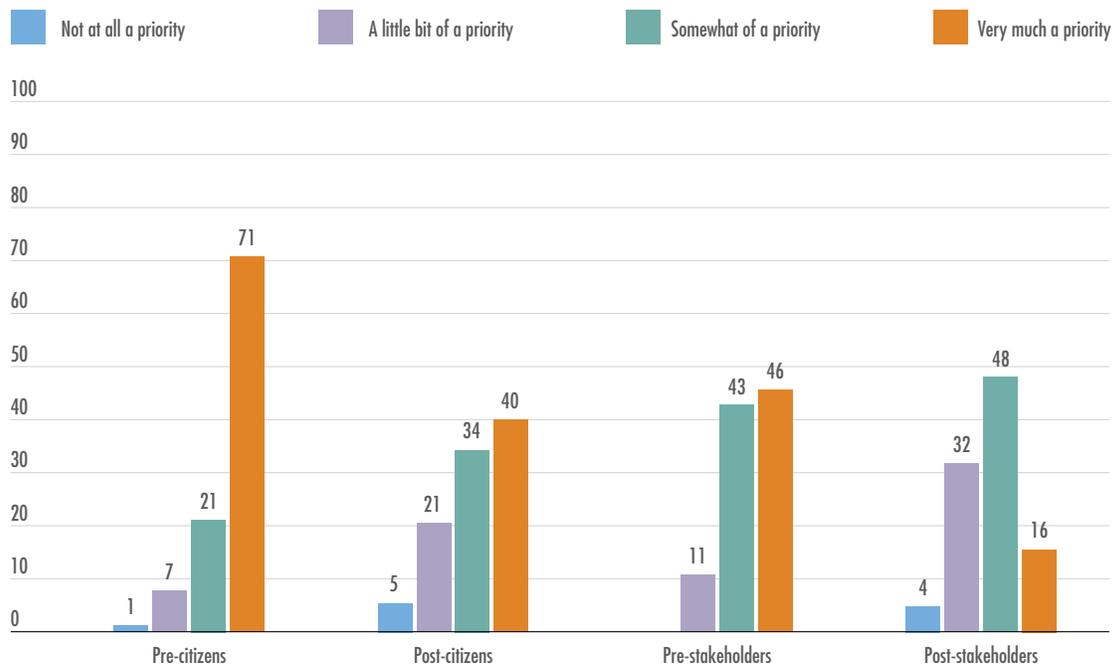
Table 2. Prioritization of people who provide health care



That said, they recognized the benefit of prioritizing individuals that support society in a variety of functions and saw a wide range of skills and services — beyond health care — that are critical to a functioning society, including individuals who maintain order, those who care for the dead, those who provide power and clean water, etc. While they understood the immediate need to address the sick, the long-term needs of a healthy society were also emphasized. Furthermore, participants expressed concern that systems of prioritization utilizing *role in society* as a criterion, beyond health care professionals, was a slippery slope. It was suggested that many individuals contribute to society in many different ways and a prioritization system could not accommodate these subtleties and still remain simple, efficient, and equitable.

Significant discussion was also dedicated to *age* considerations at each of the sessions. In the pre- and post-surveys, there was wide agreement that children should be prioritized for treatment during disasters, although the strength of these opinions lessened over the course of the meetings (see Table 3). Ambivalence was more apparent, however, in the small group discussions and within groups struggling to identify common ground.

Some individuals felt very strongly that *children* should be widely given priority for health care, either for ideological reasons (e.g., children are powerless and need protection, or children are the future of society) or because they have more life ahead of them to “save.” Participants who identified as Hispanic, in particular, felt very strongly about prioritizing children, with 70% indicating that children were “very much a priority,” as opposed to 27% of non-Hispanics. A few felt that children’s lack of self-sufficiency made them less of a priority because they do not contribute to the response to a crisis and also require caregivers. Many participants indicated they would likely forgo acceptance of medical resources if those resources would go directly to a child with a good chance of survival; but they stopped short of recommending this as a general policy due to an aversion to creating a system where medical professionals were withdrawing life-saving services which would erode trust in the system.

Table 3. Prioritization of children

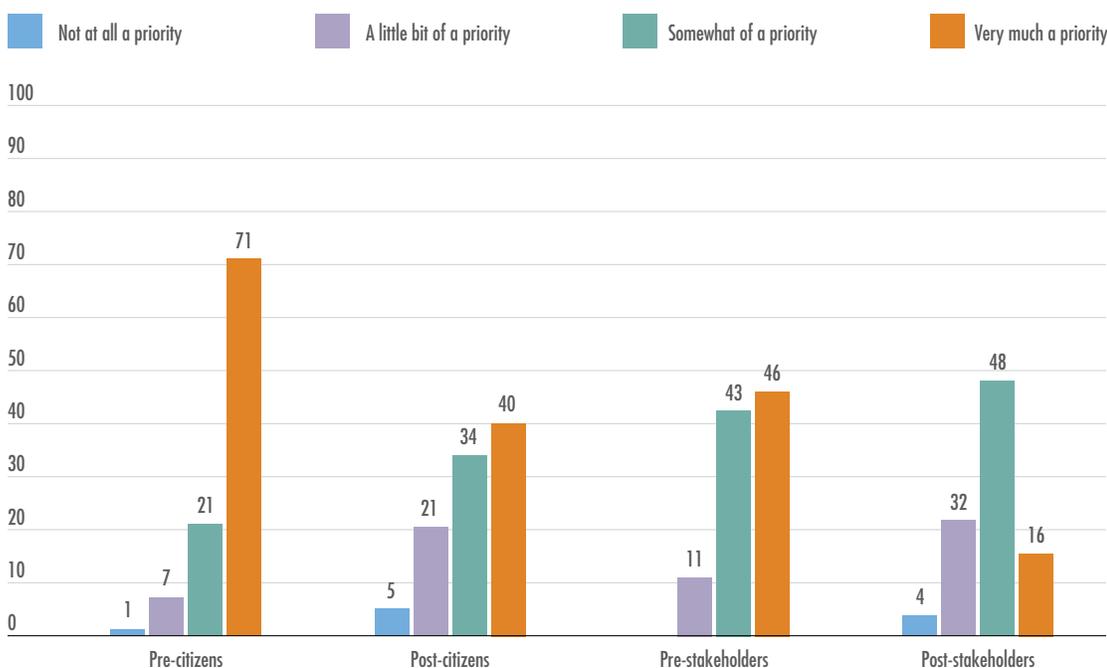
Elderly were not generally perceived as a priority group, although they were recognized by some as offering intrinsic value to society and worth prioritizing. A few people felt that it was important to include a range of all ages when setting priorities. Another group preferred to prioritize the age groups most affected by the illness, noting how some age groups were more vulnerable in previous pandemics. Overall, groups seemed to evolve over the course of the plenary discussion to reflect opinions that age should only be considered in the absence of other distinguishing factors.

Pregnant women were considered by some individuals to be a high priority due to the value of saving two lives. Most participants indicated that they would give pregnant women some level of priority, although the degree of priority varied considerably and weakened over the course of the meeting (see Table 4). Hispanic participants as a group gave higher priority to pregnant women than non-Hispanics, with 70% indicating that pregnant women were very much a priority, compared to 27% of non-Hispanics.

Standardization of the process across the state, if not the nation, was discussed in all groups to some extent and was widely seen as a means of creating equity during a time of crisis. It was also suggested that inconsistent strategies and decision-making frameworks among hospitals and regions could lead to confusion, exploitation, and possibly chaos among the general public. Some groups felt that disasters would affect regions differently, which argued against a national standard but further emphasized the value of state-level policy-making or standards. Some suggested that guidelines be developed and resources allocated at the state level to subsidize the burden on smaller jurisdictions.

Standardization with some flexibility became a widely expressed preference, to allow distribution of resources based on demand and availability within a region. Hospitals and other care facilities have different resources and different levels of care they can provide. Participants felt that disparities of care would occur if all facilities have to follow the same rigid guidelines. Medical care facilities should be able to distribute needed resources, like ventilators and staff, based on demand and availability.

Table 4. Prioritization of pregnant women



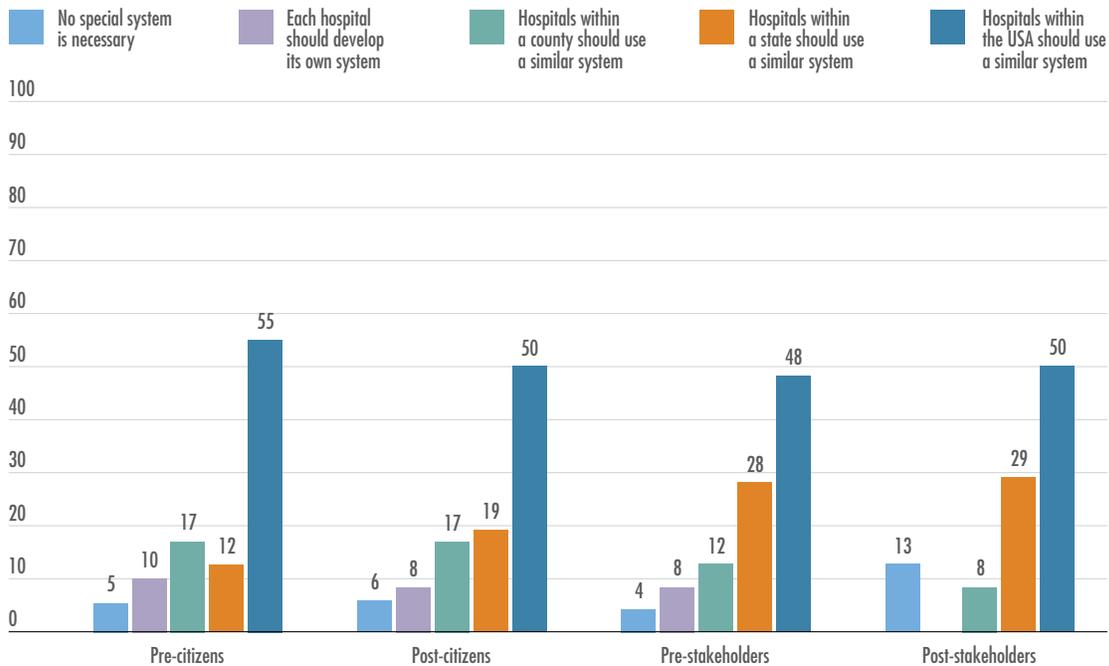
Evaluation data indicated that half of all public participants and stakeholders supported a similar system across the United States, and an additional 19% of public participants and 29% of stakeholders supported a similar system shared across an individual state (see Table 5).

Differences between stakeholder and public perspectives

Although the meetings with the general public and the key stakeholders yielded much agreement on goals and implementation of medical service prioritization during disasters, results from the Q-Sort activity suggested that there were some nuanced differences in perspective between residents-at-large and stakeholders. When the data was factor-analyzed, two main groups emerged. The first group focused on maximizing resources. They gave the most importance to survivability as a consideration in decisions about medical treatment, followed by saving the greatest number of people and using resources to help the most people, even if it lowers standards of care. Prioritizing first responders and health care workers was much less important. This first group consisted of most of the stakeholders and a much smaller number of residents-at-large. The second group appeared to focus more on response capabilities. They considered prioritizing health care workers for medical treatment as most important, followed by prioritizing first responders and saving the greatest number of people. Survivability was ranked considerably lower in importance. This group consisted largely of residents-at-large, with just a handful of stakeholders.

Although there was general agreement by participants that survivability should factor into decisions, and health care workers and first responders should have some priority, the importance given to these considerations varied between stakeholders and residents-at-large. For example, many individuals at the public meetings articulated a desire to prioritize health care workers and first responders so that they could help others when they recover, or help out during the disaster’s recovery period. Some health care providers at the stakeholder meeting, on the other hand, felt that health care workers

Table 5. Desired level of consistency



should not be give priority since the length of their recovery would not enable them to rejoin the response efforts. (However, others who work in hospital administration emphasized the need to give priority to those same workers as an incentive for them to come to work despite risk of contagion to themselves and their families.) In addition, quality-of-life post survival and length-of-life expected after survival were significantly higher priorities in the opinions of the stakeholders.

Relative to the stakeholders, members of the public reflected a much stronger priority for ensuring that everyone gets the same treatment. The South King County meeting and meeting with Spanish-speaking residents (Appendix F and G) strongly emphasized the needs of minorities and immigrant populations. They articulated the need for cultural-competency training for medical professionals and the need to address the problem that data determining survivability may be flawed by institutional racism. While the North King County group (Appendix D) would likely not strongly disagree with these points, they highlighted different considerations. They generally appeared more willing to create a system of prioritization based on role in society; though they ultimately encountered similar difficulties making determinations about different people’s worth. The group also expressed the need for the creation of a code of ethics so the people responsible for making decisions have guidelines and a protocol to follow when supplies are inadequate to meet demand. It appeared that this group contained a higher percentage of health care professionals, but it was difficult to determine if this skewed the results. The stakeholder meeting (Appendix E), by contrast, emphasized the implementation challenges associated with a complex policy and underscored the challenges experienced in a crisis situation and the need for clear direction.

Shifts in priorities over the course of the meeting

The pre- and post-survey data suggested that the exposure to the briefing by public health experts and the process of group deliberation influenced participants’ perspectives. Their answers to the evaluation

questions reflected significant movement on a few topics in particular. In general, the prioritization of any specific group diminished through the course of the meetings, most dramatically in the amount of priority they would give to children and pregnant women (see Tables 3 & 4). Those that responded that the elderly should not be a priority increased in both groups, very significantly in the case of the stakeholders. At the same time, the emphasis on survivability, length of life remaining and quality of life — with or without regard to the individual's role in society, increased. These shifts in perspective were evident in the small group discussions, where a number of participants expressed an increasing discomfort in giving priority to groups based on roles in society or age. For many of those participants, survivability seemed a less impartial criterion that would also capture some of the younger people who tend to have better ability to recover.

Values reflected in the discussions

Equity and concerns about discrimination

Participants also emphasized that anyone afflicted should be able to seek treatment without fear of repercussion. Factors that may cause this fear could include legal status, nationality, an arrest warrant, previous unpaid hospital bills, or other reasons that might be based on discrimination. A number of participants voiced concerns that some groups, such as undocumented immigrants or incarcerated people, would not have equal access to treatment or would not be eligible for access to scarce, life-saving resources. Participants in the Spanish-speaking meeting cited experiences of people in their community who had not received equitable treatment in health care facilities during the initial H1N1 influenza outbreak. They suggested that even if guidelines for medical treatment were in place, some people still might not receive equitable consideration. Others in the South King County meeting expressed their concern that survivability as a criterion in determining access to resources might be inherently discriminatory because of institutional racism in the health care system; if some groups (e.g., African Americans and immigrants) do not receive the same quality of care, then their rates of recovery and other survivability measures would be biased. It was suggested that decision-making free of discrimination not only supported the principles of fairness and equity but was practical because it would help limit the spread of a potential pandemic. Furthermore, *cultural competency* and raising the awareness of cultural issues among health care providers was suggested as an important aspect in providing this equitable system.

Several of the groups emphasized the need to address populations with *special needs*. Language barriers, sensory, and physical disabilities were most commonly noted as special needs that would require additional resources relative to another patient to adequately serve. Some people suggested that investments could be made in advance to help prepare for diverse needs. Nonetheless, most people felt that additional resources should be invested to adequately serve special needs.

It is important to clarify, however, that most people didn't think that people who face barriers to health care should get any kind of priority—their concern was about discrimination. For example, in the Q-Sort activity which asked participants to rank specific groups for prioritization, the Spanish-language participants ranked people who have difficulty accessing health care due to language barriers as a least important consideration.





Maximization of Resources

Both public participants and key stakeholders expressed a strong desire to make the best use of scarce medical resources. For many participants, prioritizing health care workers for medical treatment was a matter of maximizing resources because they believed that health care workers could help those still sick once they recovered (not because they were risking their lives nor because they should have an incentive to come to work when they might infect themselves or their families). Whether a patient was expected to survive was also an important consideration because many felt it would help ensure that medical resources would be used on those most likely to benefit and recover.

Trust in Health Care Professionals and Public Health

All groups expressed a general confidence in the *professional judgment* of medical professionals, especially in time of crisis, to make sound decisions about how to apply health care. In particular, they expressed strong faith in doctors' judgments in determining survivability of individual patients. However, they suggested that health care providers should not be placed in the difficult situation of making *value decisions* about people's lives nor should they be expected to evaluate social equity or legal boundaries. When considering the question of discontinuing care, the participants generally felt the choice should be made by the patient or patient's family rather than a doctor or health care provider. It was suggested that trust in the system and those who provide the treatment are critically important. The concern was that trust would erode quickly if resources were being taken away based on a prioritization system that would likely not be well articulated by health care professionals or understood by emotional family members and loved ones.

In general, there was also considerable trust in public health institutions, according to the pre-meeting surveys. Half of the public participants reported that they trusted the local health department to make decisions about pandemic flu "very much," with an additional 39% trusting local public health "somewhat." Figures were similar for both the state health department and CDC (see Appendix B, Tables 12 - 17).

F. Conclusions

The considerable agreement among participants at all four meetings offers a strong endorsement for an altered decision-making process for the prioritization of scarce, life-sustaining medical resources during times of disaster. Diverse residents of King County and representatives of health care, emergency management, and other key stakeholders agreed that prioritization of medical services should aim to save the greatest number of people, factoring in survivability of those treated, even if standards of care must be lowered. There was wide agreement that first responders and health care workers should be prioritized, with children and pregnant women given some priority when all other factors are equal.

The similarities between the views of the public participants and stakeholders, as well as the trust that most of the public participants placed in health care professionals and public health entities, suggests that many in the public have confidence in the decisions made by these groups to create altered standards of care for disasters. Their desire to see such decisions standardized at the state or even national level is a *call to action* for state and national policymakers to move forward with plans to establish guidelines for the health care system. Not only were the hospital administrators and health care providers in the stakeholder meeting eager for the guidance, but the general public participants felt strongly that such standardization is needed to ensure stability and fairness in the system.

While these meetings showed that the public may not be substantively different from health care providers and emergency management in discerning what system for medical service prioritization they want, they may have different needs and expectations about how policymakers, public health, and health care providers should communicate about the system. To gain the public trust and acceptance of altered standards of care, care should be taken to highlight the public's values — especially equity — when introducing and discussing them. The public must perceive that any guidelines ensure equal access, so protocols to enforce equity and deter discrimination should be made explicit, and should be emphasized in communications. The way in which these decisions are made must be transparent so that people can understand the rationale for prioritizing some groups over others, particularly in terms that explain how it may benefit the overall response to disaster and maximize resources.

The fact that many participants shifted their opinions over the course of the individual meetings points to the ability of thoughtful dialogue and educational efforts to influence public opinion. But exposing people to thoughtful discussion on these issues will be a considerable challenge in the soundbite environment of the mass media. Since it is likely that a majority of the public will not be given the opportunity to engage in carefully structured deliberation — as our public engagement participants were — communication efforts are best informed by the pre-evaluation data that show participants' opinions before they had the benefit of expert testimony or facilitated discussion. According to this data, concerns about children, pregnant women, and other vulnerable populations will likely run high, so communication must be targeted to address these concerns specifically.

Finally, to ensure public trust regarding such difficult decisions, messaging about medical service prioritization guidelines must be consistent between public health at state, local and national levels, and also between public health and the health care providers. Health care providers will play a particularly critical role as sources of information about health care treatment in disasters, given the high level of trust that the public places in them.



G. Next Steps

The findings from this project will be publicized in the following ways, to ensure that policymakers have exposure and access to this important feedback from the public:

1. At the national level:

- Findings from this project were presented to the Institute of Medicine's Committee on Guidance for Establishing Standards of Care Use in Disaster Situations Workshop on September 2, 2009. This public engagement project was referenced in the resulting document from this workshop, *Guidance for Establishing Crisis Standards of Care for Use in Disaster Situations: A Letter Report*.
- The process of this public engagement project were discussed at the Public Engagement Lessons Learned Workshop convened by the Association for State and Territorial Health Officers (ASTHO) on September 22 and 23, 2009.
- Findings will be shared with the members of the National Public Health Information Coalition (NPHIC) and Crisis And Emergency Risk Communication (CERC) advisory committee.

2. At the state level:

- Findings will be presented to the Steering Committee for Washington State Public Health Emergency Planning Regions.
- Findings will be presented at the Washington State Public Health Association Joint Conference on Health, October 5 and 6, 2009.
- This report will be provided to members of the Washington State Work Group for Altered Standards of Care.

3. At the local level

- All participants in this project will be notified of the results, and this report will be made available to them in English and Spanish.
- This report will be made publicly available on the Public Health - Seattle & King County web site.

Appendices

- A. Stakeholder Participation
- B. Survey Evaluation Results — University of Nebraska
- C. Steering Committee Members
- D. Meeting Summary — North King County - Shoreline Center 04-25-09
- E. Meeting Summary — Stakeholders - Seattle City Hall 04-29-09
- F. Meeting Summary — South King County - Auburn Senior Center 06-07-09
- G. Meeting Summary — Spanish Speakers - El Centro de la Raza 06-13-09
- H. Q-Sort Methodology
- I. Meeting Materials

Appendix A | Stakeholder Participant List

Joan Zerzan, Dietician

- University of Washington

Eileen Newton, Assistant Disaster Coordinator

- Franciscan Health System

Beth Cordova, Social Worker

- The Summit At First Hill

Stephanie Tijerina, Emergency Preparedness Coordinator

- Sea Mar Community Health Center

Anne Newcombe, Clinical Director of Emergency Services

- Harborview Medical Center

Douglas Diekema, Physician, Pediatric Emergency Medicine, Bioethics

- University of Washington, Seattle Children's Hospital

Curtis F. Veal, Jr, Medical Director, Critical Care/ICU

- Swedish Medical Center & The Polyclinic

David Hotchkin, Fellow, Pulmonary & Critical Care Medicine

- University of Washington, Harborview Medical Center

Christopher Slatore, Physician, Critical Care

- University of Washington, VA Puget Sound

Katherine Honeywell, Director of Staff Development & Medical Services

- Pediatrics Associates

Barbara Jensen, Emergency Preparedness Program Manager

- Evergreen Healthcare

Letha Mahar, RN

- The PolyClinic

Carolyn Blayney, Nurse Manager Burn/Pediatrics ICU

- Harborview Medical Center

Anna Rhys Johnson, Palliative Care Consultant, Social Worker

- Seattle Children's Hospital

Mary P. Horan, Physician Pulmonary & Critical Care, Hospital Chief of Medical Staff

- Northwest Hospital

Kim Lundgreen, Case Worker, Cultural Mediator

- Harborview Medical Center

Annette Coder, Human Resources & Safety Manager

- Multi-Service Center

Dave Eiffert, QI Coordinator/ Database Facilitator

- Catholic Community Services

Appendix A | Stakeholder Participant List - Continued

Heather Fritts, Development Director

- Center for Human Services

Donna Platt, Emergency Education Program Manager

- Hearing Speech & Deafness Center

Angela Theriault, Client Advocate

- Hearing Speech & Deafness Center

Sylvia Fuerstenberg, Executive Director

- The Arc of King County

Tsegay Burhe, Faith Leader

- Hope Eritrean Social Services & Eritrean Holy Trinity Orthodox Church

Carolyn Bilal, Faith Leader

- Idriss Mosque, Islamic Center Washington

Greg Vicars, Faith Leader

- St. Vincent de Paul Catholic Church

Pegi McEvoy, Advanced Registered Nurse Practitioner

- Seattle Public Schools

I. David Daniels, Fire Chief, Emergency Services Administrator

- Renton Fire & Emergency Services Department

Mike Muhm, Physician

- The Boeing Company

Mary Robinson, Manager Operations Continuity

- Puget Sound Energy

Appendix B | Survey Evaluation Results – University of Nebraska

Demographics

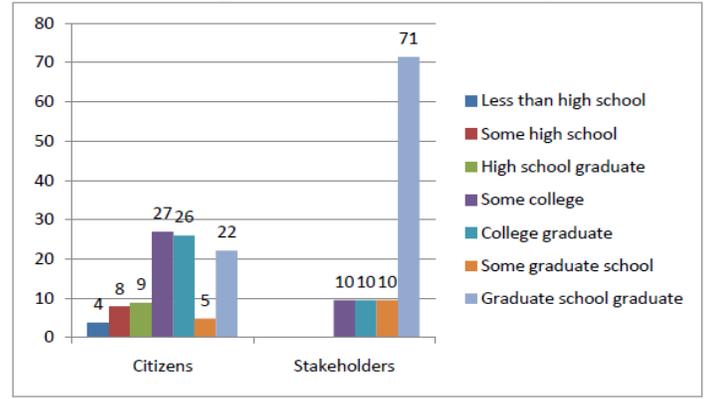
Table 1: Gender



Post-citizens, n=109

Post-stakeholders, n=21

Table 2: Highest level of education completed



Post-citizens, n=104

Post-stakeholders, n=21

Table 3: Age



Post-citizens, n=109

Post-stakeholders, n=21

Table 4: Hispanic origin or ethnic background

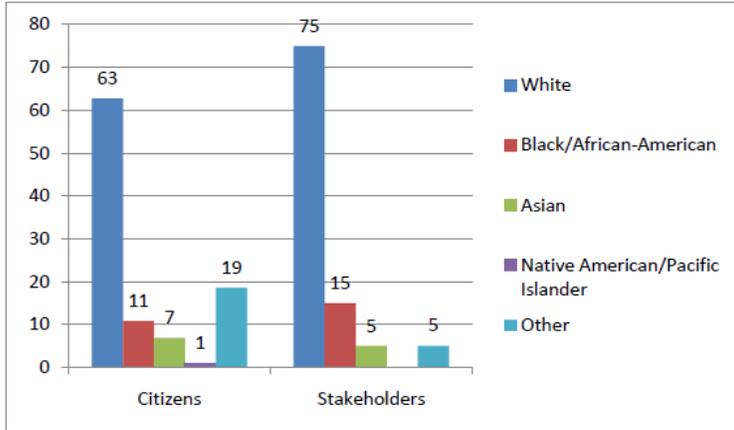


Post-citizens, n=107

Post-stakeholders, n=21

Demographics - Continued

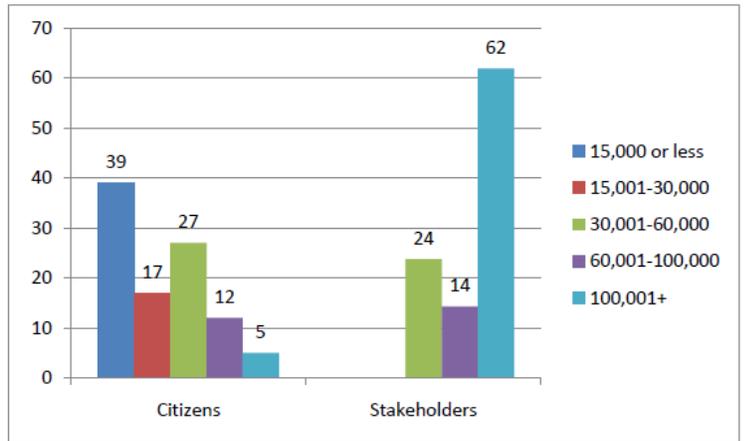
Table 5: Race or ethnic background



Post-citizens, n=102

Post-stakeholders, n=20

Table 6: Annual household income



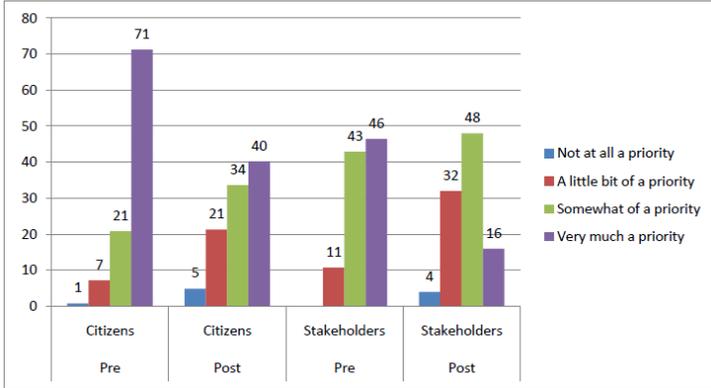
Post-citizens, n=100

Post-stakeholders, n=21

Priority for life-saving care by group

Question: If there is a pandemic flu outbreak and there are only limited medical resources, tough decisions will have to be made about who gets treatment first. Please indicate how much priority to give to each of the following groups (if all other factors are equal):

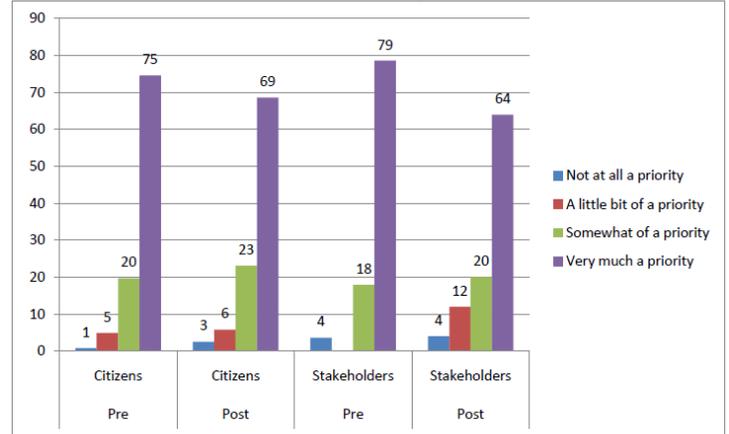
Table 7: Children



Pre-citizens, n=125; Post-citizens, n=122

Pre-stakeholders, n=28, Post-stakeholders, n=25

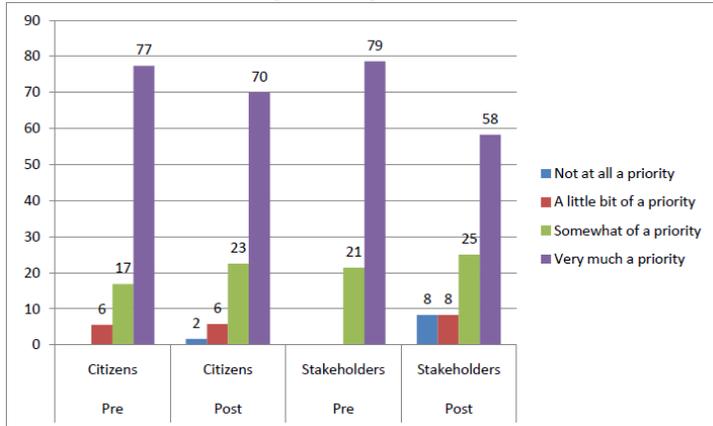
Table 8: First responders



Pre-citizens, n=122; Post-citizens, n=121

Pre-stakeholders, n=28, Post-stakeholders, n=25

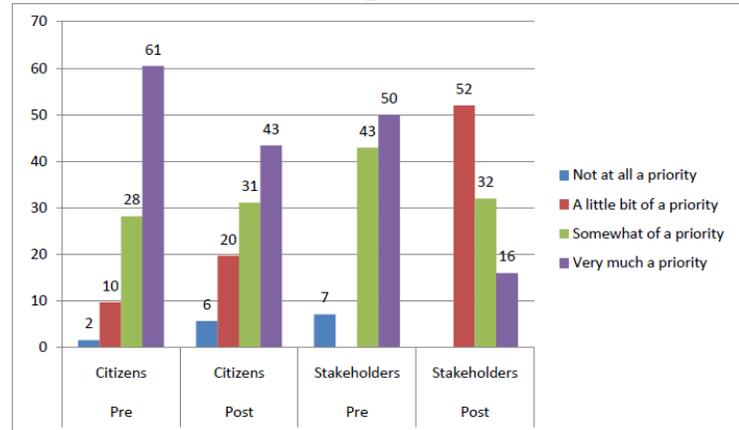
Table 9: People who provide health care



Pre-citizens, n=124; Post-citizens, n=120

Pre-stakeholders, n=28, Post-stakeholders, n=24

Table 10: Pregnant Women



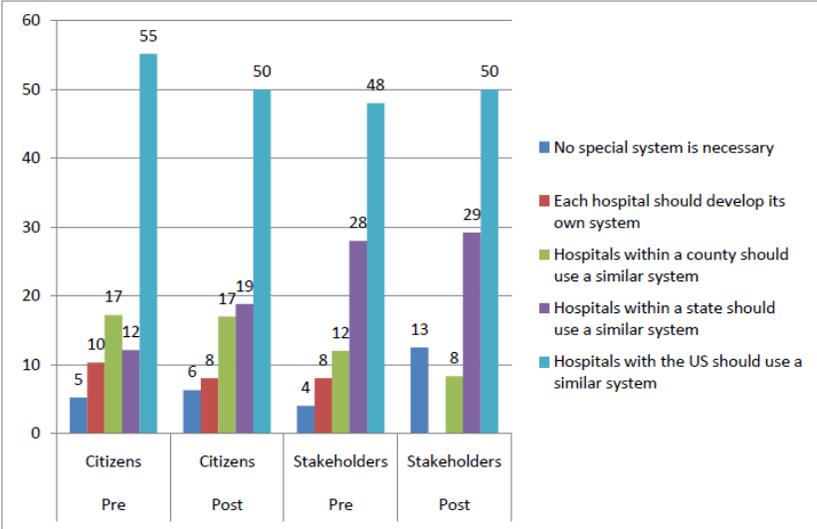
Pre-citizens, n=124; Post-citizens, n=122

Pre-stakeholders, n=28, Post-stakeholders, n=25

Standardization

Question: Decisions about medical treatment during a pandemic may be specific to each hospital, county, or state, or may even apply to the entire nation. In your opinion, at what level should decisions about medical treatment during a pandemic be consistent?

Table 11: Level of consistency



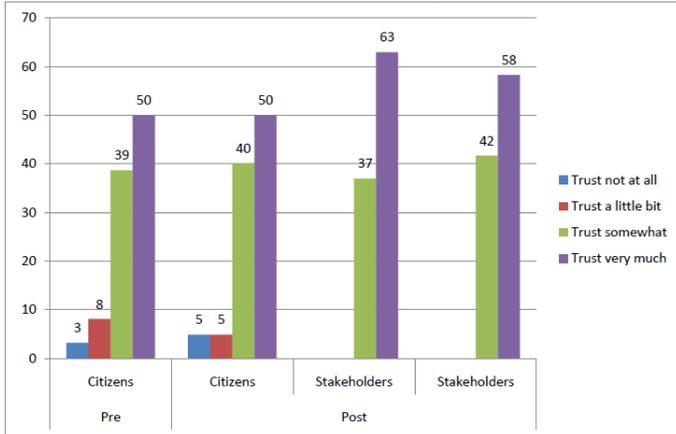
Pre-citizens, n=116; Post-citizens, n=112

Pre-stakeholders, n=25, Post-stakeholders, n=24

Trust in decision makers

Question: How much do you trust the following agencies to make decisions about pandemic flu planning and response?

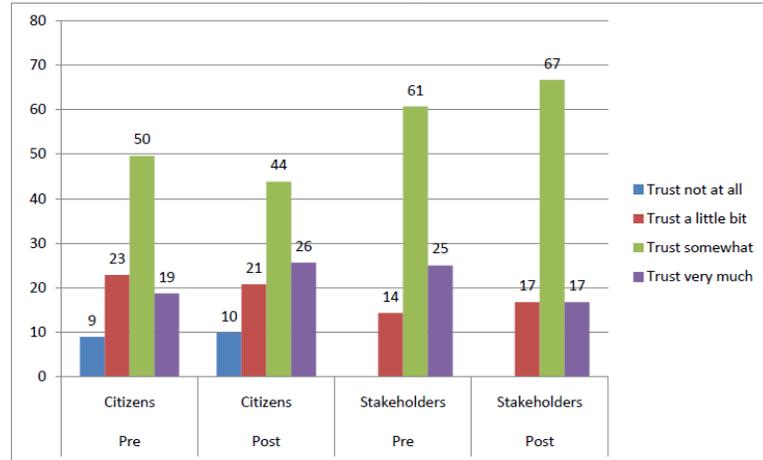
Table 12: Local health department



Pre-citizens, n=124; Post-citizens, n=122

Pre-stakeholders, n=27, Post-stakeholders, n=24

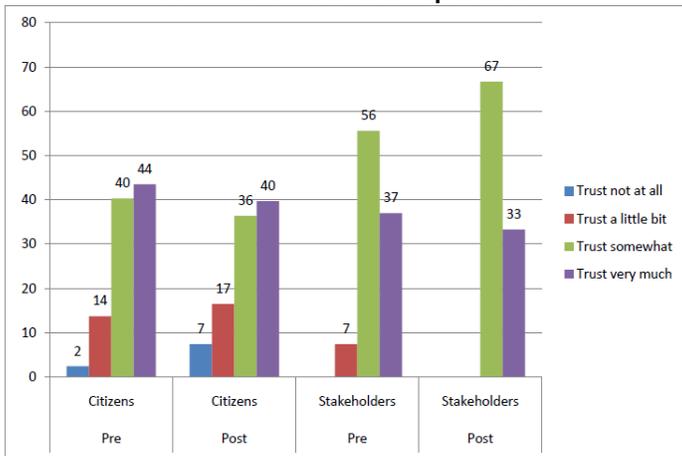
Table 13: Local government



Pre-citizens, n=123; Post-citizens, n=121

Pre-stakeholders, n=28, Post-stakeholders, n=24

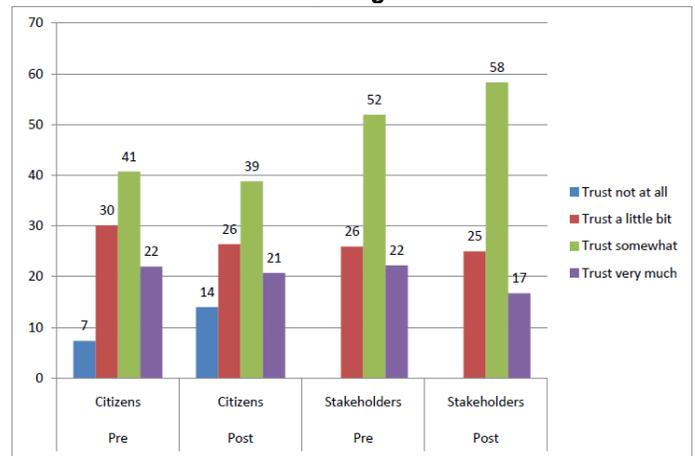
Table 14: State health department



Pre-citizens, n=124; Post-citizens, n=121

Pre-stakeholders, n=27, Post-stakeholders, n=24

Table 15: State government

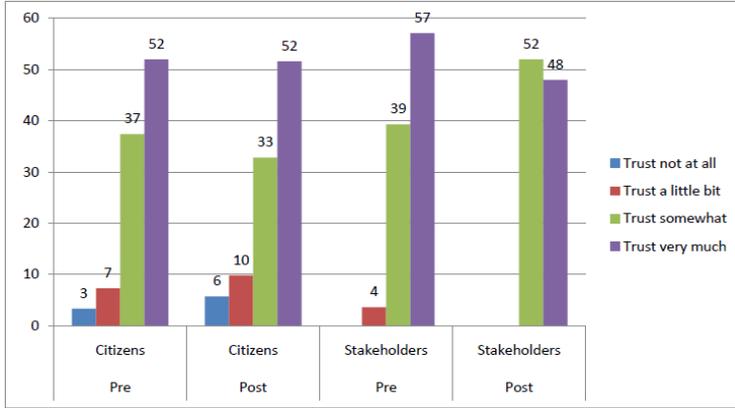


Pre-citizens, n=123; Post-citizens, n=121

Pre-stakeholders, n=27, Post-stakeholders, n=24

Trust in decision makers - continued

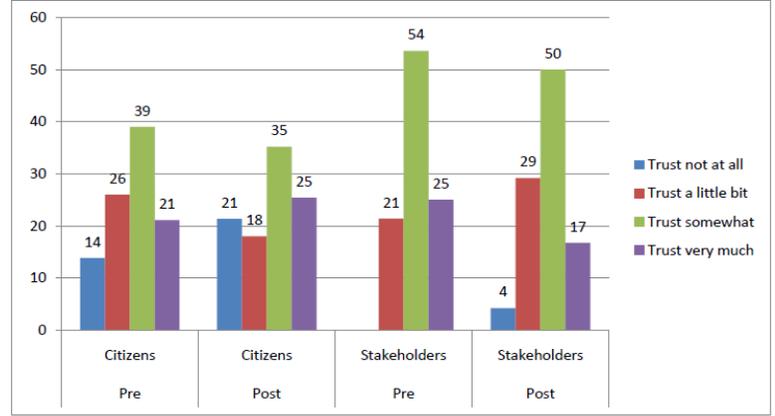
Table 16: CDC



Pre-citizens, n=123; Post-citizens, n=122

Pre-stakeholders, n=28, Post-stakeholders, n=25

Table 17: Federal government



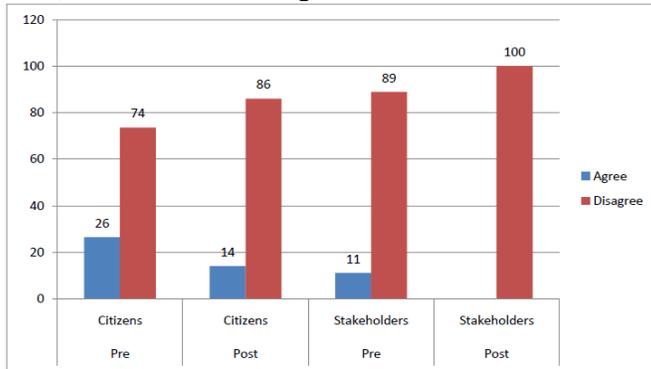
Pre-citizens, n=123; Post-citizens, n=122

Pre-stakeholders, n=28, Post-stakeholders, n=24

Goals for Medical Service Prioritization

Question: How should doctors decide which patients should get scarce, lifesaving treatment [such as hospital beds in the intensive care unit (ICU) and ventilators (machines that help people who can't breathe on their own)]? Do you agree or disagree with the following statements:

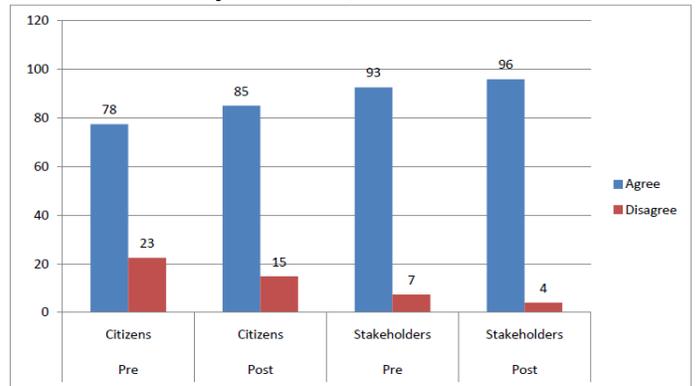
Table 18: Hospitals should provide lifesaving care on a first come, first served basis regardless of other considerations



Pre-citizens, n=121; Post-citizens, n=121

Pre-stakeholders, n=27, Post-stakeholders, n=25

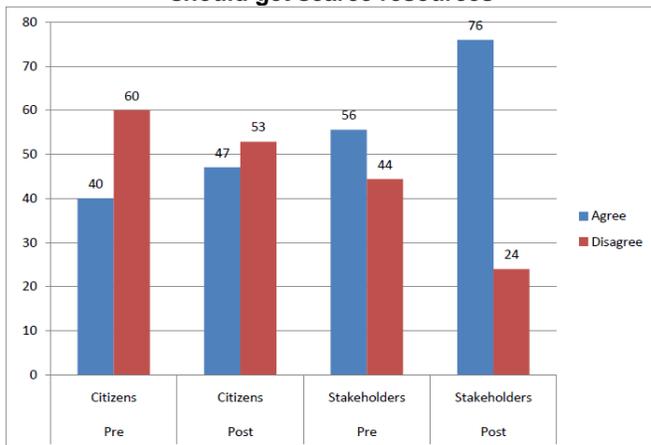
Table 19: Hospitals should take into account the likelihood of the patient surviving to avoid using scarce resources on patients who are less likely to survive, even with treatment



Pre-citizens, n=120; Post-citizens, n=121

Pre-stakeholders, n=27, Post-stakeholders, n=25

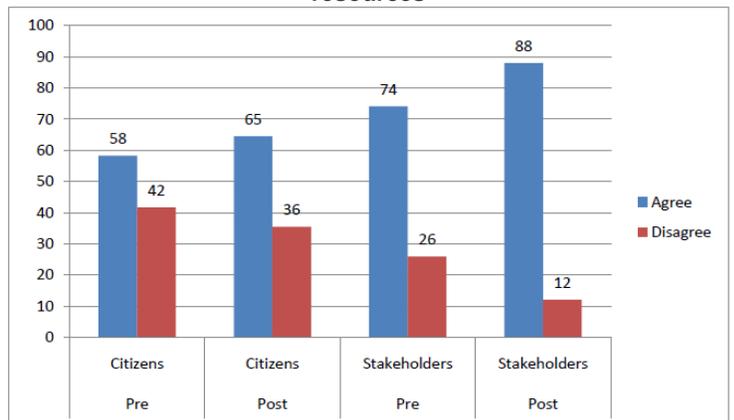
Table 20: Hospitals should take into account the number of years a person would live if they survive when deciding who should get scarce resources



Pre-citizens, n=120; Post-citizens, n=121

Pre-stakeholders, n=27, Post-stakeholders, n=25

Table 21: Hospitals should take into account the quality of life a person would have if they survive when deciding who should get scarce resources

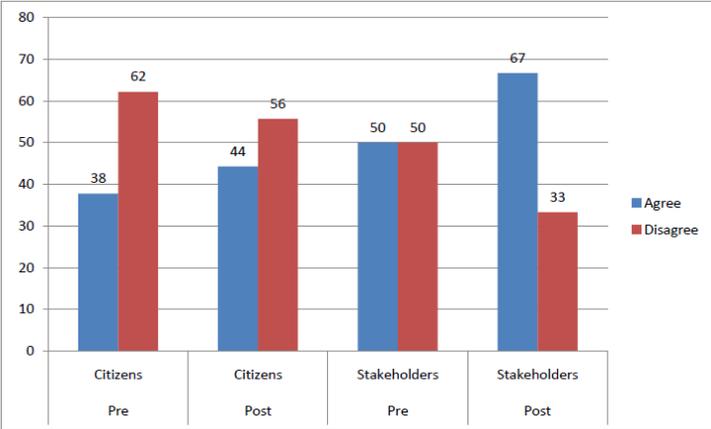


Pre-citizens, n=120; Post-citizens, n=121

Pre-stakeholders, n=27, Post-stakeholders, n=25

Goals for Medical Service Prioritization - continued

Table 22: All other factors being equal, younger people should get preference for treatment over older persons



Pre-citizens, n=119; Post-citizens, n=122

Pre-stakeholders, n=26, Post-stakeholders, n=24

Appendix C | Steering Committee Members

Washington State Department of Health

Laura Blaske

- Public Awareness and Emergency Communications Manager, Washington State Department of Health

Public Health - Seattle & King County Staff

Jeffrey S. Duchin, MD, FACP, FIDSA

- Chief, Communicable Disease Epidemiology & Immunization Section, Public Health - Seattle & King County
- Associate Professor in Medicine, Division of Infectious Disease, University of Washington

Michael Loehr

- Emergency Preparedness Section Manager, Public Health - Seattle & King County

Medical Service Providers

Lewis Rubinson, MD, PhD

- Senior Medical Consultant for Healthcare Preparedness and Response, Division of Healthcare Quality & Promotion
- Centers for Disease Control & Prevention Assistant Professor
- Division of Pulmonary and Critical Care Medicine, University of Washington, Harborview Medical Center

Jay Fathi, MD

- Chief, Dept. of Family Medicine, Swedish Medical Center Clinical Assistant Professor, University of Washington School of Medicine

Mary Beth Foglia, RN, PhD, MA

- National Center for Ethics in Health Care Department of Veterans Affairs, VA Puget Sound Health Care System

Elizabeth K Vig, MD, MPH

- Division of Gerontology and Geriatric Medicine, Geriatrics and Extended Care, VA Puget Sound Health Care System

Neil Kaneshiro, MD

- WA AAP
- Division of Pediatrics

Community Based Organizations

Beratta Gomillion

- Executive Director, Center for Human Services
- Annette Coder, PHR
- HR Manager, Multi-Service Center

Alice Kurle

- Project Manager, Hopelink

Barbara Kingsolver

- Director of King County Facilities, Catholic Community Services

Emergency Management

I. David Daniels

- Fire Chief, Emergency Services Administrator, Renton Fire & Emergency Services Department

Appendix D | Meeting Summary – North King County, Shoreline Center

April 25, 2009

I. Introduction

On April 25, 2009, Public Health—Seattle/King County, WA convened the first in a series of meetings among community members, public health experts and diverse stakeholders to better understand the public's opinions, values and priorities about how decisions are made regarding access to scarce, life-sustaining medical resources during disasters. Participants are being asked to consider how to make decisions about who gets care when there isn't enough medical staff or equipment to save everyone's life. The agenda and list of participants are included in Appendix A and B respectively.

A. Background Presentation

As background, Dr. Kathryn (Kay) Koelemay, Medical Epidemiologist for Preparedness Seattle and King County's Public Health Section provided a presentation on health care decisions in disasters. She explained the relevant characteristics of emergency medical response and healthcare systems; how disasters can impact these systems and the types of decisions that will likely need to be made about access to scarce, lifesaving resources in the event of a disaster. Additional details about the presentation are included in Appendix C.

During a disaster like a pandemic or an earthquake, resources are expected to be inadequate to meet the demand. Decisions will need to be made on the best uses of scarce resources, who should be given priority access to life sustaining treatment like ventilators and what factors should be taken into consideration when making the decision. The purpose of this meeting is to better understand the public's values and priorities so that they can inform and improve policy decisions about health care during disasters. Specific questions to be considered during the public engagement process include:

- Should the current standard of first come first served be used during a disaster?
- Should those most ill receive priority for treatment?
- Should care be prioritized based on age?
- Should those most likely to survive their illness receive priority for treatment?
- Should one's role in society be a factor in receiving scarce, live-sustaining treatment?
- Should all doctors and hospitals be expected to follow the same rules for allocation of scarce, life-sustaining treatment?
- What should be the goals in allocating scarce, life-sustaining resources?

B. Group Discussion of Background

The participants asked for additional background after the presentation. There was a combination of questions, clarifications and general comments.

If a disaster was to occur now, how would decisions be made about scarce healthcare resources? Federal guidance on vaccine prioritization has been issued. However, there is no state or federal guidance on how health care will be allocated. Hospitals may have individual plans, designed by hospital administrators, for making decisions during a disaster. What if people think that the plan at hospital A gives them a better chance for treatment than hospital B and they decide to get care at one place over another? Are people going to go to other places? This is a consideration for the discussion today, i.e., whether to create a policy that all hospitals in a region would need to comply with. Although each hospital has a plan, it may not be one that public would agree with.

How will the input from this meeting be used? During this and subsequent meetings, the Seattle and King County Health Section is engaging the public to gather input if there are better systems or perhaps a system that can be applied consistently throughout hospitals. Four meetings total will be held to discuss the health care decisions to engage the public on what is important to them and what should be considered as policies are created. The outcomes of these meetings will provide input to policies and decision-making processes to guide or direct health care decisions that the public is comfortable with and that will be effective in a disaster. This engagement process is part of a six-state CDC grant project on issues of public engagement in pandemic flu planning.

What is likelihood of flu pandemic in Washington? In the last couple days, swine flu has appeared in US and Mexico. This new flu could start to spread and become a pandemic. If WHO and CDC declare a pandemic then there is enough evidence that the virus is easily passed between people. In that case, Washington may not be able to avoid the pandemic because people travel so easily between states and countries, and if infected, may spread the disease before they realize they have it. Pandemic flu is different than seasonal flu because it is a brand new strain to which no one has immunity. The strain could be mild or severe but that is not known until the flu has started to spread.

Why can't a vaccine be manufactured before flu has spread? Vaccine manufacturers need to identify the strain of flu before the vaccine can be developed. Then, it takes months to manufacture the vaccine and produce the quantity needed.

Beyond this engagement process, what other planning is being done on a federal and state level? There is an ongoing conversation about planning for a pandemic at the federal, state, and local levels. Health care decisions are one piece of a multi-layered approach. The federal government and state governments have issued recommendations to slow the spread of the disease that include community control measures like social distancing, closing schools, and avoiding large gatherings. In addition, the federal government has released a prioritization plan for vaccine distribution.

Would conventional triage methods be used? The military uses a system to get people who are the most salvageable back on their feet. One of the considerations for this process is the priority to treat patients with the best chance of survival and who can help others. Should that be a priority in non-military settings or do we attempt to treat everyone equally no matter what their chances of survival?

Why are these questions being asked now? The way health care decisions are made has changed over the years. There is more patient input now, patients ask for options and have more participation in treatment decisions. The people that will be impacted by health care decisions in a disaster need to have input into how decisions will be made.

II. Q-sort Exercise

The Q-sort Methodology was used to address the question: How should decisions be made about rationing limited, life-sustaining resources? The activity was designed to help us understand what considerations are most important to the participants when it comes to decisions about health care treatment during disasters. This was accomplished by having the participants sort 27 statements (see Appendix D) taken from real opinions given by members of the general public, community advocates, and health care experts. Participants sorted the statements based on what they felt was most important and least important to them.

A. Q-Sort Small Group Synthesis

After working through the Q-sort exercise individually, participants discussed the statements they felt were the most and least important in small groups. Many of the groups found common ground on some of their most important and least important considerations, though differences of opinion still remained.

Most Important Considerations

Participants conveyed a strong message that any system prioritizing health care during a disaster should aim to provide services to *the greatest number possible*, even if the level of care would not be the same level experienced during a non-emergency. Participants were generally comfortable relying on medical professionals to make triage decisions to help ensure the greatest number possible received treatment and were more comfortable with medical professionals making medical decisions rather than spending their time and energy attempting to develop or implement a complicated system of patient priority. When considering patient priorities, however, participants were generally supportive of providing this priority to *doctors, nurses and medical workers*. There was some discussion about providing this priority as an incentive to these workers because they were selflessly risking their lives; but this was a minority view. Many of the participants were doctors, nurses or medical workers and noted how these workers were engaged in this career of service and would find that more of a reward than a priority treatment incentive, but the priority for this group was also deemed important as a way to

protect the basic health care provision infrastructure to enable the perpetuation of the system to provide treatment to the greatest number of people over time.

Following this rationale, of preserving the health care provision infrastructure, many participants indicated that all *first responders* should receive treatment. Though this sentiment was strongly supported, it was not as universally supported as priority for doctors, nurses and medical workers. While this type of prioritization did receive strong support, some began to worry that it might be a large enough group and difficult enough to track that it could make implementation of the system complicated. Generally the group was willing to consider a system of prioritization based on roles individuals played in the society up to the point that it made the system complicated and unwieldy. *Quickness and simplicity* were deemed more important than fairness. Again this was more commentary as a means to achieve the goal of treating the greatest number of patients possible during the time of emergency rather than commentary about fairness. Fairness was an important goal to participants, but not to the extent that it would result in a complicated system that would be difficult to administer.

Using *age* as a criterion was important to many participants, but also had its detractors and ultimately there was no real consensus on how age should be used. Some participants felt strongly that age should not be a consideration and that decisions should be based only on medical need or survivability. Participants prioritized the very young and elderly because their age made it likely that they would be particularly vulnerable. Other age groups were prioritized because their age placed them in the demographic that would be the most able to help during a disaster. Children were also prioritized by some because they were deemed to be resilient and able to recover more quickly and have a better chance of survival than an older person. Ultimately, the strongest sentiment regarding the age criterion was a perspective repeated by many individuals that they would likely give up treatment of themselves to enable a younger child with a high likelihood of survival to receive treatment since they had a greater chance of a longer life ahead.

Least Important Considerations

One of the messages expressed with the most consistency during the day was that health care decisions and priorities should *not be based on a patient's ability to pay*. This message was expressed in a number of ways and multiple times. Participants felt strongly that everyone should have access to health care regardless of their ability to pay and decisions should not be made on the basis of wealth. Some outlying voices expressed concerns that people with wealth would be able to manipulate the system or there is need to ensure people are paying for the system so that it can be maintained, ability to pay was generally rejected as a selection criteria.

Participants did note a need for a prioritization system since treating on a *first come, first serve basis* would be chaotic. The same feelings were expressed for *random selection* of patients that would not take into account the seriousness of the illness or the necessity of stopping a pandemic. Participants generally believed that even though decisions are tough, they need to be made.

Other Prioritization Factors

Participants discussed the difficulty inherent in assigning a value to a person's life. Many factors were discussed and many different ideas considered. For example, how should the disabled be considered? What about people who cannot speak English well and do not have the ability to get care if they want to? Conflicting feelings were voiced about whether criminals and those on death row should be treated differently. The groups expressed a desire for fairness but realized that fairness is complex and becomes more complicated when you consider the consequences of difficult decisions. Participants added that fairness will be hard to judge with limited resources.

Some participants felt the decisions would change based on the specific situation. For example, the 1918 Spanish flu disproportionately affected young healthy people. If certain demographic groups are affected more than others, that group might need to be prioritized. Participants did feel, however, that using race, gender, or religion could lead to discrimination and should not be a factor a prioritization system.

B. Q-Sort Plenary Session Discussion

In the follow-up, large group discussion there was emphasis of the point that ability to pay should not be the deciding factor. Many groups discussed prioritizing a person's role or occupation as an important factor. However, they felt that first responders and other jobs related to healthcare were not the only priorities. Individuals maintaining basic social services, infrastructure and utilities, public safety and other activities required to support healthy people were also vital during a disaster. New questions surfaced about which groups should be prioritized by occupation. For example, if medical care givers with licenses are prioritized, what about someone experience as a caregiver but has no license? Ultimately, many began to feel concerned about making prioritizations based on societal role due to the difficulty in developing an appropriate system, among other concerns.

The group did continue to support the idea that doctors, nurses, and medical workers should get priority for medical care, but the question of "incentive" generated conflicting feelings that evolved throughout the day. Some participants felt strongly that health care providers should be prioritized because they will be treating the sick everyday and may have to choose between going to work and staying home to care for sick family members. They felt that if doctors and nurses are willing to risk their welfare then we should look out for them and help them to stay healthy. Others felt that if medical providers receive prioritization, they should be required to perform their job for the benefit of others (i.e., if they are not willing to help others then they should not be given priority). Some felt strongly that while doctors and nurses should be given priority for treatment, the promise of treatment should not be an incentive to get them to work. In contrast, some participants felt that health care providers choose to join that profession with an understanding that they will take on risks and will continue to work without an incentive. While it was acknowledged that doctors, nurses, and health care providers that receive priority may not recover during the height of the pandemic to provide further assistance, it was generally acknowledged that their recovery would be important to the basic infrastructure of the health care system and might even provide relief for tired aid givers at the tail end of a pandemic, in addition to the fact that they would live to continue to treat patients after the crisis was over.

When the groups discussed the desire for fairness they reiterated the difficulty developing a system that was simple and fair. One participant expressed that his least favorite decision, randomly choosing patients for treatment, could become his most favorite. The participant explained that in the case of a pandemic flu outbreak, the majority of the population will survive unaffected. A random approach to decision making may end up being the fairest means of determining who lives. Others disagreed and believed that even though the decisions are tough, they need to be made. Generally the group wanted to treat the greatest number of patients but was unclear about the best way to accomplish that goal.

One participant expressed that his least favorite decision, randomly choosing patients for treatment, could become his most favorite. The participant explained that in the case of a pandemic flu outbreak, the majority of the population will survive unaffected. A random approach to decision making may end up being the most fair means of determining who lives. Others disagreed and believed that even though the decisions are tough, they need to be made.

When asked about considerations missing from the Q-sort statements, participants mentioned the following.

- Race, gender religion and other characteristics that could lead to discrimination should not be a factor in prioritization
- Individuals who help keep the peace and maintain law and order should receive consideration
- Patients with other medical conditions should continue to receive care.
- Criminals and those on death row received should receive consideration (different opinions expressed)
- There is a need for continuing to improve communications during a disaster since good communications can help make resources go further
- There is a need to get information out to help people (patients and medical professionals) make better decisions, minimize chaos, and re-direct people to alternate appropriate resources

III. World Café

Small groups of eight were asked to consider a series of hypothetical scenarios or “vignettes” intended to help participants to personalize the kind of decisions that will need to be made in the case of influenza or another severe pandemic. Using a “World Café” style process, participants moved through a suite of three vignettes in small groups. Each group was asked to build on the discussion of the previous group as part of a progressive conversation integrating the ideas of all perspectives into a coherent outcome. Groups were asked to carry the thinking from the previous group into their conversations. The vignettes, associated questions and discussion are included in Appendix E. The following section (IV. Closing Discussion) provides a high-level summary of key points the participants raised in plenary discussion based on their small group World Café vignette conversations.

IV. Closing Discussion

At the end of the day participants returned to their original small groups and revisited their Q-sort boards to make changes based on the perspectives they heard over the course of the day. Many said they made few changes to their Q-sort. The morals and values reflected in their decisions remained the same, but this event helped them to understand that situations can be complex and there is a need to dig deeper to understand the underlying issues and unintended consequences of their decisions.

Changes and Key Themes

During the group discussion at the end of the meeting participants were asked if their opinions changed over the course of the day. A few admitted that they had changed opinions, many indicated there was learning but no significant shift in their thinking, and only a few responded that the day's discussion validated what they already thought. The participants found that making these decisions was harder than they had expected, especially when they realized not everyone would receive care. Some felt they needed more information about each patient in the vignettes to make good decisions, though it was recognized that health care providers are often making decisions without complete information. Others suggested that too much information was given for some patients – more than a medical professional would have - which made it harder to make the decisions. Participants, however, generally seemed to support the need for making a system as simple and as efficient as possible while ensuring it did not unfairly discriminate against some group.

Code of Ethics and Consistency

One overarching suggestion was to create a code of ethics so the people responsible for making decisions have guidelines and a protocol to follow when supplies are inadequate to meet demand. The participants generally felt it was beneficial to create some consistency among hospitals because the decisions should not be arbitrary or vary significantly from hospital to hospital. However, many participants agreed that while high level guidelines could help, decisions should be made on a case by case basis. Toward the end of the day, the group's discussion focused increasingly on the code of ethics that drives health care providers. They felt that even in a crisis, established values and the public's trust in a high ethical standard should not be compromised.

Survivability and Roles

Factors consistently supported by participants were survivability, long-term quality of life and priority for doctors, nurses and health care providers. The overarching consideration should be providing care to the greatest number of people based on who is most likely to survive and live a high quality of life. There was trust in medical professionals to make these decisions based on their training. It should be noted, however, that there is a distinction between the decisions made by a doctor based on what is best for the individual patient vs. a holistic consideration for society that should be considered when creating priorities for patient treatment.

On one hand many participants were strongly supportive of providing priority to doctors, nurses and health care providers. This was quickly followed by priority for first responders generally and those who maintained important

societal infrastructure. Others, however, became increasingly emphatic about the reality that many roles are important to maintain a functioning society, in addition to medical providers. Some asked if a very sick police officer who is not likely to survive should not be given priority over a single mother who is likely to survive if given treatment, or if an EMT should be prioritized over an artist who many make a great contribution to society in a different way. Ultimately medical providers generally received the highest level of support for priority within the overarching goal of providing the best treatment possible to the greatest number of people based on likelihood of survival.

Off Limits Criteria

The group was asked whether any factors should be off the table. They reiterated the opinion that ability to pay should not be a deciding factor in whether a patient receives care or not. They also continued to feel that decisions should not be made randomly.

Appendix E | Meeting Summary – Stakeholders, Seattle City Hall

April 29, 2009

I. Introduction

On April 29 2009, Public Health—Seattle/King County, WA convened the second in a series of four meetings among community members, public health experts and diverse stakeholders to better understand the public's opinions, values and priorities about how decisions are made regarding access to scarce, life-sustaining medical resources during disasters. Thirty stakeholder representatives from community partners, including healthcare, human service organizations, and emergency management were invited to participate in the session. Participants represented a wide-range of community organizations and agencies, including:

- Immigrant and refugee service providers
- Homeless and housing service providers
- Community health clinics
- Hospitals and health care providers
- Sensory disability service providers
- Physical disability service providers
- Developmental disability service providers
- Home healthcare agencies
- Local law enforcement
- Emergency response and management
- Nursing and adult living homes
- Faith-based organizations
- Social service and advocacy organizations serving diverse populations

Participants were asked to consider how to make decisions about who gets care when there isn't enough medical staff or equipment to save everyone's life. The agenda and list of participants are included in Appendix A and B respectively.

A. Background Presentation

As background, Dr. Lewis Rubinson, MD, PhD, Senior Medical Consultant for Healthcare Preparedness and Response for the Division of Healthcare Quality & Promotion, CDC and the Division of Pulmonary and Critical Care Medicine at the University of Washington, Harborview Medical Center, provided a presentation on health care decisions in disasters. Dr. Rubinson explained the relevant characteristics of emergency medical response and healthcare systems; how disasters can impact these systems and the types of decisions that will likely need

to be made about access to scarce, lifesaving resources in the event of a disaster. Additional details about the presentation are included in Appendix C.

During a disaster, like a pandemic or an earthquake, resources are expected to be inadequate to meet the demand. Decisions will need to be made on the best uses of scarce resources, who should be given priority access to life sustaining treatment like ventilators and what factors should be taken into consideration when making the decision. The purpose of this meeting is to better understand the public's values and priorities so that they can inform and improve policy decisions about health care during disasters. Specific questions to be considered during the public engagement process include:

- Should the current standard of first come first served be used during a disaster?
- Should those most ill receive priority for treatment?
- Should care be prioritized based on age?
- Should those most likely to survive their illness receive priority for treatment?
- Should one's role in society be a factor in receiving scarce, life-sustaining treatment?
- Should all doctors and hospitals be expected to follow the same rules for allocation of scarce, life-sustaining treatment?
- What should be the goals in allocating scarce, life-sustaining resources?

Dr. Rubinson concluded by emphasizing the following key assumptions that each participant was asked to remember during the discussions.

1. We are only discussing life saving care.
2. There are not enough of the life-saving medical resources to treat everyone who needs them.
3. People who do not get life saving care will most likely die.
4. The majority of the population will survive the flu pandemic.

B. Group Discussion of Background

The participants asked for additional background after the presentation as summarized below.

How will the criteria or guidelines be passed on to citizens? Today's discussion can help decision-makers determine what values are important to the stakeholders of health care decisions. Using the values learned here as a guide, they can create operations plans that the public would be comfortable with. Health care coalitions can work with the hospitals to get their buy in and figure out ways to provide the information back to the community. The first key step is to find out what are the driving values, which can inform policy makers.

Can we look to other sources, like military triage, rather than start from scratch? Military triage handles young, healthy people who have suffered a serious injury during combat. During a disaster, it will be much more difficult to use that system because of the complexity of medical issues. There has been outreach to military and science

fields on the best ways to determine care; but, there was a gap with community engagement, which this process is trying to fill.

II. Q-Sort Exercise

The Q-sort methodology was used to address the question: *How should decisions be made about rationing of limited, life-sustaining resources?* The activity was designed to help us understand what considerations are most important to the participants when it comes to decisions about health care treatment during disasters. This was accomplished by having participants sort 27 statements (see Appendix D) taken from real opinions given by members of the general public and health care experts. Participants sorted the statements based on what they felt was most important and least important to them.

A. Q-Sort Small Group Synthesis

After working through the Q-sort exercise individually, participants discussed the statements they felt were the most and least important in small groups. Many of the groups found common ground on some of their most important and least important considerations, though differences of opinion still remained.

Most Important Considerations

Over the course of the conversations, the criteria of survivability became increasingly important among all participants. In order to use resources efficiently, priority for medical care should be given to the patients with the best chance of survival. Moreover, priority should be given to patients who will survive and have a good quality of life. In some cases, resources might be better used on the patient who is not as severely ill rather than consuming a lot of resources on a patient that is not likely to survive. The groups agreed that the chance of survival trumps role in society and age because it doesn't matter how valuable your skills are or how many years you have left to live if you are not likely to survive the flu. Furthermore, co-morbidity should be a factor; patients, who don't have other medical conditions, have the greatest chance of survival.

Role in Society

Many people felt that first responders and medical professionals should have priority because they are needed to maintain essential services and offer the skills necessary to treat the sick. They felt roles should be prioritized to some extent but it was hard to define which roles would be the most important for society. Some participants did not want to place a value on the patients' lives but others noted that the decision is not that some lives are more valuable, it is about who is essential right now.

Some participants thought priorities should be set based on who can help the most after they recover. People who could help sustain infrastructure and vital services such as power, water and maintaining order were prioritized as congruent with the theme of helping the greatest number possible. Participants wanted to take into account societal value of each patient's role but they recognized how difficult it would be to implement a system

that relied upon detailed personal information. Some participants felt that it will be hard for doctors to obtain background information, like occupation, about the patients so decisions shouldn't be based on that criteria. Additionally, trying to gather information may be to the detriment of the patient because it will delay treatment. The health screening is more important than other factors like age, occupation, and family.

The participants felt that medical professionals and first responders should not get lifesaving care if they are severely ill because they will not be back on their feet for a long time. Representatives from the hospitals felt strongly that health care professionals should not get preferential treatment. On the other hand, a representative from a community-based organization did not agree because doctors and nurses risk their lives to treat ill patients.

Incentives

The participants had a lengthy discussion about incentives. Some health care workers will not want to come to work so an incentive could be necessary to ensure that hospitals are fully staffed. Some acknowledge that society might need to offer incentive to get them to leave sick family and friends in a time of crisis to help the greater population. Another participant pointed out that employers have an obligation to protect their employees and employees will expect care if they get sick while they are doing their jobs. Participants felt strongly that if health care providers receive treatment, they must treat patients when they recover. Others felt that there was no way to make such a commitment. Other participants felt that incentive wasn't the right term. Resources like childcare will have to be made available to health care providers.

Age Considerations

Many participants believed that age should be considered since there is a higher likelihood of survival for younger patients. However, it should be considered only in combination with the patient's resilience and ability to respond to treatment. Others felt that decisions should be made based solely on the patient's medical condition, not their age. One suggestion was to multiply the likelihood of survival with number of years they have to live and use that to make the decision. In addition, participants felt that quality of life after survival should be a factor. There was fairly broad consensus that while it is important to save the most years, the remaining years should have a good quality. Nevertheless, all recognized that it is impossible to judge quality of life for another person.

Adjusted Standard of Care

The group widely agreed that during a disaster, we won't be able to afford to provide the same standards of care we expect now. It was most important to offer the greatest good for the greatest number. Participants felt that there should be an attempt to save as many lives as possible while using resources in the most efficient way. In a flu pandemic, getting people treated quickly is more important than making sure it is fair.

There was more discussion among the stakeholders on the need for standards and guidelines. The group felt that care should be allocated, not just granted, and be the most efficient use of available resources. The participants

felt that there should be guidelines for hospitals and they should be standardized and consistent at the state level. Some suggested that resources should be allocated at the state level to take the burden off smaller jurisdictions. There was concern that if people know that King County has more resources they may come from other areas for treatment. Hospitals have different resources and different levels of care they can provide. Participants felt there will be disparities of care if all hospitals have to follow the same rigid guidelines. Hospitals should be able to distribute needed resources, like ventilators and staff, based on demand and availability. Additionally, there was a suggestion to make regulations, not guidelines, so that people know there will be repercussions if they try to bend the rules.

Least Important Considerations

Participants agreed that ability to pay was among the least important considerations. All people should be able to receive care regardless of whether or not they can pay. Similarly, a person should not receive preferential treatment based on their ability to pay. Participants also felt that it is important to have prioritization guidelines and avoid a first come, first serve situation. They felt that patients who don't need treatment will come to the hospital because they will want first access to care which could lead to unnecessary hospital visits in an already stressed system.

They also felt that random selection should not be used because it would slow treatment and is not the best use of resources. Some participants admitted to feeling that it will be too hard to choose between patients with similar ages and prognoses and thought that random selection among them would be the best way to make the choice. They suggested creating a selection tier that include prognosis, expertise, age, and the status of patient's dependents and, after that has been completed, then the decision should be made randomly or by first come, first serve. People recognized that it would be difficult if not impossible to collect such personal information.

Other Prioritization Factors

A range of views was expressed about the priority of caregivers. Some participants felt they should receive priority. However, others felt that since there were so many, that would overwhelm the system and wouldn't help to narrow the priorities in a meaningful way.

Some felt pregnant women should be prioritized because two lives were at stake. Most people agreed that all else being equal, saving two lives was a priority.

Many people thought that patients, who are able, should have input in decisions about their care. However, even though decisions made by family are very important, the family may not be consulted in a disaster in the same way they would be under normal circumstances.

There were also concerns related to the withdrawal of care. Most participants felt that care should not be withdrawn unless another patient has a better chance of survival. Many people felt withdrawal of care was unacceptable if the individual's life was at stake.

One participant noted that some of the criteria being discussed are discriminatory, including the prioritization of care based on age or marital status. Another participant expressed concern that focusing on survivability and specific careers could lead to indirectly to ethics issues. There was also concern that this group shouldn't be making decisions about what is best for society and another person's quality of life. The participants wrestled with belief systems, and it was suggested that prayer and spirituality should be a source of guidance when facts are not conclusive.

Some participants did not like the idea of giving priority to certain demographic groups, they did not want to focus on demographics over the level of care needed. In the end they decided that some sort of prioritization is needed but should be referred to as triage and should not be based on prioritization of a one demographic group over another.

One participant pointed out that people who do not speak English will have a hard time being assessed since doctors may not want to take the time to figure out how to communicate with them. It was recommended that some thought needs to put into unique communication needs of various audiences. It was also pointed out that certain populations might need extra resources and hospitals should be willing to invest in those resources – for example services to address the language barrier. Another participant noted that currently these services would not be available and while it would be nice to provide them, it would be very difficult if the resources weren't already in place when the disaster happens.

Taboo

Race, gender or cultural bias should not be part of the decision making process. Although there was a suggestion that immigration status should be a factor in some cases. One small group decided that criminal record should not be considered, that prisoners should receive care and the fact that they are incarcerated should be low in the decision making process.

B. Q-Sort Plenary Session Discussion

Participants acknowledged the difficult decisions that health care providers are faced with when resources are inadequate to save all those that need them. Participants noted that they interpreted the Q-sort statements differently among the individuals in the group. They felt that the choices were easy at first, but as they discussed choices with other participants the decisions became more complicated and choices more difficult.

Participants discussed their desire to prioritize societal roles in some way. A doctor's skills are important and those who can help address the current situation or help maintain essential services will be needed throughout

the disaster. There a consensus that the goal of saving the greatest number of people even if some may not be treated—was among the most important factors. The group was conflicted over the population specific statements. They decided that survivability should come first then contribution to society and population related statements would be less important.

The participants had a lengthy discussion about whether doctors, nurses and medical workers should get priority for medical care as an incentive to show up for work when they may be worried about catching the flu. Some health care workers won't want to come to work so an incentive could be necessary. It was suggested that the incentives will get people to work but the risk is that a health care workers receives treatment and then refuses to treat other patients. The group agreed that least important statement are first come first serve, ability to pay, and random selection.

The statements didn't mention end of life care - our culture is already grappling with end of life decision making and considering the resources and type of care to provide people who are at the end of their lives. Some feel that those who are at the end of life care stage would feel like they are giving life to others by letting them have treatment.

III. World Café Vignettes

Small groups of eight were asked to consider a series of hypothetical scenarios or “vignettes” intended to help participants to personalize the kind of decisions that will need to be made in the case of influenza or other severe pandemic. Using a “World Café” style process, participants moved through a suite of three vignettes in small groups. Each group was asked to build on the discussion of the previous group as part of a progressive conversation that integrates the ideas of all perspectives into a coherent outcome. Groups were asked to carry the thinking from the previous group into their conversations. The vignettes, associated questions and discussion are included in Appendix E. The following section (IV. Closing Discussion) provides a high-level summary of key points the participants raised in plenary discussion based on their small group World Café vignette conversations.

IV. Closing Discussion

At the end of the meeting, participants were asked if their opinions changed over the course of the day. A few admitted their opinions had changed and a few indicated the discussion validated what they already thought. The majority indicated they felt more knowledgeable and had a deeper understanding of different perspectives based on their conversations in the room.

Changes and Key Themes

One of the changes noted in the plenary was a shift toward more efficient decisions making. If the prioritization criteria are complicated then it will slow things down and in the end it is more important in a crisis to treat people quickly than fairly.

Some of the stakeholders felt that over the course of the conversation it had become clear to them that we are expecting our doctors and first responders to do things they are not trained for. This group shouldn't be making decisions about what is best for society and another person's quality of life.

The medical professionals are not trained to make judgments about value to society and value of life. They are trained to administer medicine and if we haven't trained them to assess broad societal values then they shouldn't be making decisions based on such expertise.

At the end of the day, participants noted that the criteria of survivability had become more important throughout the discussions. Additionally, some of the participants from outside the health care system realized that incentives for health care providers probably will be needed to ensure that hospitals are fully staffed.

Participants wanted to take into account societal value of each patient's role but doing so became very complicated. They felt roles should be prioritized to some extent but it was hard to define which roles would be the most important for society. The individual's needs are the emphasis, in health care now, but in a disaster that needs to become an emphasis on society's needs.

There was more discussion among the stakeholders on the need for standards and guidelines. The group felt that care should be allocated not just granted. These are tough decisions and not all the population will agree with guidelines once they are established.

Appendix F | Meeting Summary – South King County, Auburn Senior Center

June 7, 2009

I. Introduction

On June 7, 2009, Public Health—Seattle/King County, WA convened the third in a series of four meetings among community members, public health experts and diverse stakeholders to better understand the public's opinions, values and priorities about how decisions are made regarding access to scarce, life-sustaining medical resources during disasters. Participants are being asked to consider how to make decisions about who gets care when there is not enough medical staff or equipment to save everyone's life. The agenda and list of participants are included in Appendix A and B respectively.

A. Background Presentation

As background, Dr. Kathryn (Kay) Koelemay, Medical Epidemiologist for Preparedness Seattle and King County's Public Health Section provided a presentation on health care decisions in disasters. She explained the relevant characteristics of emergency medical response and healthcare systems; how disasters can impact these systems and the types of decisions that will likely need to be made about access to scarce, lifesaving resources in the event of a disaster. Additional details about the presentation are included in Appendix C.

During a disaster, like a pandemic or an earthquake, resources are expected to be inadequate to meet the demand. Decisions will need to be made on the best uses of scarce resources, who should be given priority access to life sustaining treatment like ventilators and what factors should be taken into consideration when making the decision. The purpose of this meeting is to better understand the public's values and priorities so that they can inform and improve policy decisions about health care during disasters. Specific questions to be considered during the public engagement process include:

- Should the current standard of first come first served be used during a disaster?
- Should those most ill receive priority for treatment?
- Should care be prioritized based on age?
- Should those most likely to survive their illness receive priority for treatment?
- Should one's role in society be a factor in receiving scarce, live-sustaining treatment?
- Should all doctors and hospitals be expected to follow the same rules for allocation of scarce, life-sustaining treatment?
- What should be the goals in allocating scarce, life-sustaining resources?

Dr. Koelemay concluded by reiterating the following key assumptions each participant was to remember during the discussions.

1. We are only discussing life saving care.
2. There are not enough of the life-saving medical resources to treat everyone who needs them.
3. People who do not get life saving care will most likely die.
4. The majority of the population will survive the flu pandemic.

B. Group Discussion of Background

The participants asked for additional background after the presentation. There was a combination of questions, clarifications and general comments.

What percent of the population perished due to Spanish Flu? About one third of the general population became ill but only two percent of those sick perished.

Are masks effective? Masks can be most effective to limit spread if worn by those who are sick. It is also effective to use the “Dracula cough” approach, coughing into ones arm, rather than into the hands since bacteria is easily spread by the hands.

When was the cholera outbreak? Cholera can happen even today in many different countries.

Is this typical to have a venue like this? Why are you doing this? It is not typical to have public engagement like this, although it has happened previously for community containment measures for the spread of disease that would affect things like school closures, for example. This event is being held because there are few opportunities for the public to provide input into policy development. It is also important to have these events to help educate people and create the understanding that we will have to make difficult decisions. Because this was considered important Public Health sought grant funds from the Centers for Disease Control (CDC) to get input from the public to help inform policy development. The goal is to continue the discussion.

Can you explain triage? Triage is from a French word that means sorting and is a way to make quick decisions on who to treat first. Triage happens at many different levels from individual family decisions to EMT response all the way through the hospital system. One approach could be to do the most for the greatest number of people and this approach is often used on the battlefield. There are different types of triage and it would be helpful to receive input on the type of criteria that should be considered when making these sorting decisions.

Is it true that we are about 1,000 years overdue for a major earthquake that could kill thousands of people in the Seattle area? Yes there are major fault lines that run through this area and we are in earthquake county. The chance of a 6.7 earthquake or higher in the next 50 years has been estimated at 80%

Can you hold discussions like this in the future with children? Yes, we understand more and more that children have unique and creative ideas that often adults do not consider and there are efforts to involve children.

If there is a major disaster, are there ways to utilize those who were not hurt to help with the response? Yes, there are a variety of different programs depending on where you live and resources and materials will be distributed at the end of the workshop that show ways people can become more directly involved. The Certified Emergency Response Team (CERT) is one example and there is also a teen CERT program.

In Taiwan there are many disaster education programs that are on TV and other popular media. Why do we not do more of this in the United States? The United States has been fortunate to suffer fewer large disasters and there is a general sense of denial. With examples such as 9/11 and Katrina there is more awareness. There are indications that the Vietnamese community in New Orleans was one of the first rebuilt because of their experience with disasters. We need to continue to learn from examples and work to educate more people in forums such as this.

Is Washington prepared? If a disaster happened would we know what to do? There is certainly a lot of planning and preparedness but not everyone would know what to do and there is more that can be done. These questions have been asked for a long time with a number of people and these are the types of questions that need to be grappled with on an ongoing basis.

Why are these questions being asked now? The way health care decisions are made has changed over the years. There is more patient input now, patients ask for options and have more participation in treatment decisions. The people that will be impacted by health care decisions in a disaster need to have input into how decisions will be made.

What are we going to do with all this information? Where will it go? The notes from all workshops will be put into summary reports and shared with the steering committee for this project. Several committee members are policy makers and involved in policy formation so that discussion will help determine appropriate next steps with the information. Ultimately the goal is to use this information to help inform policy development. It will also go to the CDC which is the Federal agency that helps set national policy. This engagement process is part of a six-state CDC grant project on issues of public engagement in pandemic flu planning.

II. Q-sort Exercise

The Q-sort Methodology was used to address the question: How should decisions be made about rationing limited, life-sustaining resources? The activity was designed to help us understand what considerations are most important to the participants when it comes to decisions about health care treatment during disasters. This was

accomplished by having the participants sort 27 statements (see Appendix D) taken from real opinions given by members of the general public, community advocates and health care experts. Participants sorted the statements based on what they felt was most important and least important to them.

A. Q-Sort Small Group Synthesis

After working through the Q-sort exercise individually, participants discussed the statements they felt were the most and least important in small groups. Many of the groups found common ground on some of their most important and least important considerations, though differences of opinion still remained.

Most Important Considerations

The concept of providing treatment for the *greatest number possible* was strongly supported by participants even if it compromised the ability to provide the same level of care as given in non-emergency situations. Treatment of the greatest number and providing priority to doctors, nurses and medical workers was reiterated among all groups. Participants may have initially felt that providing priority to doctors, nurses and caregivers was justified as incentive to get them to show up for work when they might be scared of catching the flu or as reward because of their difficult job; but groups seemed to move towards supporting the prioritization because doctors and nurses help others to survive. This notion of preserving the infrastructure and ability of society to respond to crisis was congruent with the theme of treating the greatest number possible.

First responders (firefighters, police, ambulance workers) were also deemed worthy of prioritization by some, yet not to the same degree as doctors and nurses. The support for first responders was often because they were viewed as helpful to everyone; but it also came from the perspective of preserving the infrastructure that provides societal response to disaster. Disagreement began to emerge during discussion of first responders as some felt it moved down the slippery slope of providing prioritization based on *roles*, an idea not as universally supported. Some felt that it was very important to provide prioritization for those who served critical roles in society that would help the greatest number survive. But support for role prioritization began to diminish as participants talked about the many different people who provide critical roles in different ways, the difficulty in determining who played what role and the difficulty in developing and administering a system with this level of complexity. Support began to emerge for *efficiency* and *fairness*. Participants wanted a system that did not hamstring healthcare providers with complexity and allowed for efficient delivery of services and also provided all segments of society with equal access to these resources.

When discussing the issue of age participants gravitated towards supporting youth. Participants often conveyed this sentiment in the first person, indicating they would make the personal decision to give limited resources to children over themselves. Through discussion, however, participants began to support the concept of working to preserve a *societal range of ages* as an attempt to maintain societal stability and continuity. The concept of working to preserve *families* was voiced, in addition to *survivability*. Participants generally trusted the professional judgment of doctors, nurses and caregivers to determine who had the greatest likelihood of survival and provide resources to those individuals.

Least Important Considerations

Participants repeatedly indicated that *ability to pay* should not be a determining factor in who receives treatment. While some expressed concerns about the viability of the system, ability to pay was repeatedly mentioned as one of the least important considerations. Participants supported the notion that health care should be provided and accessible to all. Participants also indicated that both *randomization* and a *first come first serve* basis of prioritization would be chaotic, would likely not provide the greatest number with the ability to survive and would limit the ability of medical workers to use their professional judgment about survivability.

The issue of *roles* that individuals played in society was discussed and discouraged as a prioritization factor not only because of the difficulty in weighing the relative value of different roles, but because participants did not want to force care givers to make value choices that would be difficult to substantiate and articulate. While some individuals indicated that making *fair* decisions was less important than treating people as quickly as possible, discussion generally revealed a preference for both fairness and efficiency. It was acknowledged that creating a fair system that provided equal access to all segments of society would be difficult, but it was supported as a laudable goal. From a practical perspective, however, it was suggested that the system should be simple enough to create efficient decision making and maximize the efficient delivery of services to the population. Considerations that impeded that goal were discouraged.

Other Prioritization Factors

Participants acknowledged that it would be ideal if treatment could be provided to those who had the greatest likelihood of living many additional years; but it was viewed as unreasonable to make both this determination and determinations about who was likely to have a greater quality of life upon survival. A tension was recognized between the need to follow protocol vs. the need to provide treatment quickly and efficiently. It was also suggested that a prioritization system should be relatively simple to address the difficulty obtaining verifiable history and to not be overly influenced by the demands of a hysterical patient. Participants also warned against cultural bias and suggested diligence in the creation of a system to help raise cultural awareness and perpetuate equality. Generally participants warned against perpetuating racism or discrimination of all marginalized groups, including prisoners. The discussion about prisoners was not universally supported, nor was discussion about prioritizing pregnant women, but participants did support making determinations based on expert opinions about survivability and efforts to create a prioritization system that provide fair and equal access. A few participants voiced concern that data determining survivability estimates may be flawed by institutional racism in medical research and treatment.

B. Q-Sort Plenary Session Discussion

Participants recognized this is a difficult process because as humans we want to say that everyone should have the right to live rather than make tough choices. It was also acknowledged that the responses given were based on previous knowledge and preconceived biases, though this was tempered by listening to the opinions of others

and learning through the workshop process. Participants generally indicated a desire to *treat the greatest number* possible and do better than a “first come first serve” system of prioritization. Participants were also comfortable giving priority to doctors, nurses, and first responders, but as a measure to help ensure the disaster response system stays intact rather than as a reward for the difficulty of their job. Even if the doctors and nurses were to not recover in time for the immediate response to the particular disaster in question, they were viewed as part of the important healthcare and emergency response infrastructure for the future and would be needed in the recovery period. The other sentiment conveyed by the group was that *ability to pay* should not be a determining criterion in who should receive care. Though some participants gently asked who would pay for the system, discrimination against the poor and vulnerable populations was strongly criticized. In other words, a value expressed by the group was that all individuals should not fear to come to the hospital nor be turned away because of an inability to pay, legal status or other issues that may give pause.

While discussing the need to protect *vulnerable populations* and the importance of valuing all human life, some participants raised concerns about making sure the incarcerated were not forgotten. While the value of saving human life was expressed and supported, some participants also expressed concerns about giving priority to individuals that had already negatively impacted society. This was countered by a warning against “profiling” when creating a system of priority.

When considering *age*, participants generally considered children important because they are going to provide the future. Some indicated children would take less resources because they are more resilient while others reminded the group that the young have been disproportionately affected in past pandemics and youth can have disabilities and sicknesses as well. Due to these reasons, and the fact that many different individuals with a wide variety of skills are needed to keep society intact, it was suggested that an effort should be made to save the whole range of the population and keeping families intact to the greatest extent possible. The idea of making choices based on *survivability*, who had the greatest likelihood of survival, was expressed. In other words, efforts should be made to help the greatest number and it was a better use of limited resources to help many people rather than dedicate those resources to a few people who are most sick. Participants also reinforced the idea that patients should have an individual right to refuse treatment to allow those resources to be used on someone else and many people indicated they would make that choice to benefit a child or young adult.

When considering the issue of *standardization* across the state and the country, participants generally supported the idea for all areas to have similar guidelines and policies. If these guidelines were not biased they could level the playing field giving equal access and opportunity to all. Participants also emphasized the importance of getting good information to community groups to help give disadvantaged groups better access to medical treatment.

Other Considerations

Participants also made a few key points that were related to the question of prioritizing limited resources. *Disseminate Resources to Community Centers* - While the questions were geared towards thinking about limited

resources at the hospitals, participants suggested there should be a strong effort to disseminate key information and resources to the many community centers across the state because they would more effectively reach a greater number of people and would keep the hospitals less crowded and more able to deal with the most sick.

Bias and Cultural Competency – Participants indicated that the system placed a tremendous amount of responsibility on the doctors and nurses and while they were generally trusted they should receive additional cultural competency training to help ensure that biases or lack of understanding of different cultures was not discriminating against certain segments of the population. *Oversight* – There was a lot of discussion about triage, morality and decisions but there was little discussion about who is overseeing those who are making the decisions (the doctors and nurses) to make sure decisions are made in a similar way and giving equal opportunity to all.

III. World Café

Small groups of eight were asked to consider a series of hypothetical scenarios or “vignettes” intended to help participants to personalize the kind of decisions that will need to be made in the case of influenza or another severe pandemic. Using a “World Café” style process, participants moved through a suite of three vignettes in small groups. Each group was asked to build on the discussion of the previous group as part of a progressive conversation integrating the ideas of all perspectives into a coherent outcome. Groups were asked to carry the thinking from the previous group into their conversations. The vignettes, associated questions and discussion are included in Appendix E. The following section (IV. Closing Discussion) provides a high-level summary of key points the participants raised in plenary discussion based on their small group World Café vignette conversations.

IV. Closing Discussion

At the end of the meeting, participants were asked if their opinions changed over the course of the day. A few admitted their opinions had changed and a few indicated the discussion validated what they already thought. The majority indicated they felt more knowledgeable and had a deeper understanding of different perspectives in the room. When asked if perspectives were more similar or dissimilar, participants reported there was mature debate and benefit from listening to many perspectives in the room. It should be noted, however, that participants may have underreported the extent to which their opinions may have changed during the workshop. In at least one small group discussion the participants first indicated their opinions had not changed when they had the opportunity to revisit their Q-sort statements. When the group re-reported their most and least important statements at the end of the day, there were more changes than would have been expected based on their initial characterization of limited change.

Changes and Key Themes

Some of the *changes* reported in the plenary discussion were a shift from prioritizing the elderly and disabled to prioritizing the young. Participants also indicated that while they had always prioritized doctors and nurses they did so more because of their ability to help others rather than as a reward for the difficult and jeopardizing work they do. The group continued to emphasize the importance of *survivability* as a treatment prioritization criterion to

help reach the goal of treating as many people as possible. The question of *roles* was met with mixed reactions. Many participants were supportive of doctors, nurses and potentially first responders receiving prioritization because they can help support the healthcare infrastructure that can provide treatment to the greatest number possible. Participants seemed to support a system that would best help society get through the difficulties presented by the crisis or disaster in question. There was discussion about the need for many different roles in society and participants began to shy away from supporting a system that would prioritize treatment based on the role one played in society. The determination of such a system would not only be complicated and difficult to administer but it was unclear who would make the determinations, administer the system and how it could be equitable. It was suggested that nobody would want to hear that their loved one was not provided care because they did not play a sufficiently supported role in society, so this criterion should not carry as much weight. Support for *equity* became more strongly supported than determinations based on role.

Standardization, Equality and Cultural Competency

Participants were also generally supportive of a prioritization system that was standardized across the state, provided it was fair, supported the greatest number possible and did not disadvantage one area over another. There was more divergence regarding support for national standards because of concern that disasters or pandemics would affect different areas differently. It should be highlighted that standardization was particularly supported as a vehicle to provide fair and equitable care to all populations. To this end it was noted that current statistics and systems are based on institutionalized racism or preferences for the dominant populations in society and efforts to raise the bar for all should be considered in the development of a new system of prioritization with the goal of systemic equality. *Cultural competency* and raising the awareness of cultural issues among healthcare providers was suggested as an important aspect in providing this equitable system.

Discontinuing Care

When considering the question of discontinuing care the participants generally felt the choice should be made by the patient or patient's family rather than the decision of a doctor or healthcare provider. It was suggested that trust in the system and those that provide the treatment is critically important and that trust would erode quickly if resources were being taken away based on a prioritization system that would likely not be well articulated by healthcare professionals or understood by emotional family members and loved ones. Again the idea of cultural sensitivity was highlighted.

Off-Limits Criteria

Three main points emerged from the discussion when participants were asked if any criteria should be considered off-limits, or not part of any treatment prioritization system. The first was *ability to pay*. Participants repeatedly emphasized that treatment should be provided whether a person had the ability to pay or not. Participants also emphasized that anyone afflicted should be able to seek treatment *without fear of repercussion*. Factors that may cause this fear could include legal status, nationality, a warrant for their arrest, previous unpaid hospital bills, or other reasons that might be based on discrimination. It was suggested that this was not only supported by the principles of fairness and equity but was practical because it would help limit the spread of a potential pandemic.

Finally, participants suggested that caregivers should not be placed in the difficult situation of making *value decisions* about people's lives; they should give care.

Other Issues

Participants also raised additional points in closing. They re-emphasized the need for unbiased standards and protocols to limit the ability for bias to influence on-site decision making or prioritization. They discouraged the use of a randomized system as unwise and suggested that "first come first serve" could be biased because some people may not be able to get to a care facility as quickly as others due to a lack of resources, a disability, language barrier or similar issues. They also re-emphasized the need to ensure rural facilities have the ability to respond and that appropriate resources are distributed to community centers to help with distributed response and to minimize a rush on the hospitals. Participants also raised the question of who would oversee the system to ensure that it was being fairly administered and appropriately providing the greatest benefit to the most number of people.

Appendix G | Meeting Summary – Spanish Speakers, El Centro de la Raza

June 13, 2009

I. Introduction

On June 13, 2009, Public Health—Seattle/King County, WA convened the fourth in a series of four meetings among community members, public health experts and diverse stakeholders to better understand the public's opinions, values and priorities about how decisions are made regarding access to scarce, life-sustaining medical resources during disasters. Participants in this meeting were primarily Spanish-speaking and were provided with simultaneous interpretation. Additionally, all meeting instruments and materials were translated into Spanish and facilitators of the plenary session and small group sessions were bilingual speakers.

Participants were asked to consider how to make decisions about who gets care when there is not enough medical staff or equipment to save everyone's life. The meeting agenda is included in Appendix I.

A. Background Presentation

As background, Carlos Dominguez, MPH, MHA, Department of Environmental and Occupational Health Sciences University of Washington, provided a presentation on health care decisions in disasters. He explained the relevant characteristics of emergency medical response and healthcare systems; how disasters can impact these systems and the types of decisions that will likely need to be made about access to scarce, lifesaving resources in the event of a disaster. Additional details about the presentation are included in Appendix C.

During a disaster, like a pandemic or an earthquake, resources are expected to be inadequate to meet the demand. Decisions will need to be made on the best uses of scarce resources, who should be given priority access to life sustaining treatment like ventilators and what factors should be taken into consideration when making the decision. The purpose of this meeting was to better understand the public's values and priorities so that they can inform and improve policy decisions about health care during disasters. Specific questions being considered during the public engagement process included:

- Should the current standard of first come first served be used during a disaster?
- Should those most ill receive priority for treatment?
- Should care be prioritized based on age?
- Should those most likely to survive their illness receive priority for treatment?
- Should one's role in society be a factor in receiving scarce, life-sustaining treatment?
- Should all doctors and hospitals be expected to follow the same rules for allocation of scarce, life-sustaining treatment?

- What should be the goals in allocating scarce, life-sustaining resources?

Carlos Dominguez concluded by reiterating the following key assumptions each participant was to remember during the discussions.

1. We are only discussing life saving care.
2. There are not enough of the life-saving medical resources to treat everyone who needs them.
3. People who do not get life saving care will most likely die.
4. The majority of the population will survive the flu pandemic.

II. Q-sort Exercise

The Q-sort Methodology was used to address the question: How should decisions be made about rationing limited, life-sustaining resources? The activity was designed to help us understand what considerations are most important to the participants when it comes to decisions about health care treatment during disasters. This was accomplished by having the participants sort 27 statements taken from real opinions given by members of the general public, community advocates and health care experts. Participants sorted the statements based on what they felt was most important and least important to them.

A. Q-Sort Small Group Synthesis

After working through the Q-sort exercise individually, participants discussed the statements they felt were the most and least important in small groups. Many of the groups found common ground on some of their most important and least important considerations, though differences of opinion still remained.

The most important and least important considerations in rationing life sustaining resources among the Spanish speaking participants mirrored those that were considered by participants in the first three meetings, as reiterated below. A distinct difference with the participants in the Spanish speaking meeting was the *heightened sensitivity and concerns about discrimination and immigration issues as they would affect decision-making policies and practices*. It was a raised concern among the participants that anyone afflicted should be able to seek treatment without fear of repercussion, including any reasons that might be based on discrimination. Participants cited experiences of people in their community who they felt had not received equitable treatment in health care facilities during the initial H1N1 influenza outbreak to suggest that even if guidelines for medical treatment were in place, some people might not receive the same consideration.

Most Important Considerations

The participants stressed the issues of treating all *equitably* and factoring in *survivability* as the most important considerations in determining decision making priorities. Treating as many people as possible would maximize resources. The groups agreed that the chance of survival trumps role in society and age because it doesn't matter how valuable your skills are or how many years you have left to live if you are not likely to survive the flu.

Least Important Considerations

People with the ability to pay should be the first to get medical care is the least important consideration.

Other Prioritization Factors

As stated above, equity in treatment and concerns about the impacts of discrimination were repeatedly mentioned as very important issues to address when determining policies and practices for prioritizing medical treatment during a pandemic.

III. World Café

Small groups of eight were asked to consider a series of hypothetical scenarios or “vignettes” intended to help participants to personalize the kind of decisions that will need to be made in the case of influenza or another severe pandemic. Using a “World Café” style process, participants moved through a suite of three vignettes in small groups. Each group was asked to build on the discussion of the previous group as part of a progressive conversation integrating the ideas of all perspectives into a coherent outcome. Groups were asked to carry the thinking from the previous group into their conversations. The vignettes are included in Appendix I.

IV. Closing Discussion

At the end of the meeting, participants were asked if their opinions changed over the course of the day. A few admitted their opinions had changed and a few indicated the discussion validated what they already thought. The majority indicated they felt more knowledgeable and had a deeper understanding of different perspectives based on their conversations in the room.

Changes and Key Themes

Some of the participants felt that over the course of the conversation it had become clear to them that we are expecting our doctors and first responders to do things they are not trained for. This group shouldn't be making decisions about what is best for society and another person's quality of life. The medical professionals are not trained to make judgments about value to society and value of life. They are trained to administer medicine and if we haven't trained them to assess broad societal values then they shouldn't be making decisions based on such expertise.

Participants also noted that there is a need for personal responsibility to protect their own health and limit the spread of disease; but, there is a need for the government to provide sufficient and understandable information to the public on the means and resources available to achieve this objective.

At the end of the day, participants noted that the criteria of survivability had become more important throughout the discussions. Participants wanted to take into account societal value of each patient's role but doing so became very complicated. They felt roles should be prioritized to some extent but it was hard to define which roles would be the most important for society. The individual's needs are the emphasis, in health care now, but in a disaster that needs to become an emphasis on society's needs.

There was more discussion on the need for standards and guidelines. The group felt that care should be allocated not just granted. These are tough decisions and not all the population will agree with guidelines once they are established.

Appendix H | Q-Sort Methodology

Tool development and pre-testing

We used Q methodology as a means to stimulate conversation about this topic and to gain an understanding of different ways of seeing the problem at hand. Q method requires the rank ordering of a series of opinion statements about the topic. We gathered the opinion statements through conversations with key informants and members of the public along with a reading of the black and grey literature on the topic. Once we had a universe of approximately 165 statements, we whittled them down into a manageable grouping of 80 statements, by combining similar statements and weeding out others that weren't precisely about the topic. At the end of this process we had approximately 40 statements. We then extensively pre-tested the statements to assure that the statements were appropriate to the topic, clearly written and understandable and distinct from each other. We also asked pre-test participants to suggest statements that were missing. At the end of the process we had 27 statements.

Use of Q method at Public Engagement Meetings

We began the small group discussions by providing each participant with a plastic baggie containing the 27 statements, along with a Q board to be used for sorting (ranking) the statements. Each participant put his or her initials on the Q board. The statements had stuck to the Q board with Velcro strips. The participants sorted the statements according to a condition of instruction that required ranking the statements from "least important consideration" to "most important consideration." (See Appendix I. Meeting Materials for a list of the Q-sort statements)

The facilitator led a discussion about participants' choices and rationale for how they placed statements, particularly those statements that were sorted as "most" and "least" important. A notetaker took notes during the discussion.

At the conclusion of the World Café discussions, participants returned to their original tables and were provided with their Q boards. They were invited to make changes if they had changed their opinions based on the day's activities and discussions. Some participants did make changes. Another discussion was held, aimed at coming to consensus around statements. Finally, the notetaker noted how each participant sorted the statements.

Analysis

The sorts were entered into the PQMethod software program. [<http://www.lrz-muenchen.de/~schmolck/qmethod/downpqx.htm>]. Two factors were extracted using Principal Components factor analysis method. Factor rotation was obtained using Varimax rotation.

Appendix I | Meeting Materials

1. Annotated Meeting Agenda

Public Engagement Meetings on Medical Service Prioritization During an Influenza Pandemic

Meeting Objectives

These meetings are being conducted to better understand the public's values and priorities related to delivery of altered standards of medical care during a severe influenza pandemic, including restrictions on access to care and to limited potentially life-sustaining medical resources. Specifically, the public will be asked to address the following questions:

1. Should we alter standards of care during an influenza pandemic? If yes:
2. What should be the goal of altered standards of care?
3. How should decisions be made about rationing of limited, life-sustaining resources?
4. Should altered standards of care be standardized?

Background Material and Handouts

Background materials on Pandemic Influenza

Logistics

- *Room arrangement: Participants will be seated in rounds of approximately 8 people each.*
- *Table-top discussions will have a facilitator. The facilitation team will be a mix from Seattle & King county Staff, Meridian Staff and ICMA Staff. Total facilitators needed will vary depending on the number of participants.*
- *Include nametags for participants to facilitate conversations as individuals move from one table to another.*
- *Name tags will be coded to reflect table assignments so that the individuals know where to go for each session.*

Agenda

9:00 am Registration, Breakfast, and Pre-Evaluations

9:15 am Welcome and Introductions

Welcome from hosts. Orient the group to the goals and methods for the meeting. Participants will be asked to introduce themselves during the small group exercises. Key people will be introduced to the full group.

9:20 am Background

Provide presentations on:

- Health Care Decisions in Disasters (40 minutes)
- Q&A (25 minutes)

10:25 Break

10:40 am Q-Sort Methodology

Q-sort will be used to address the question: How should decisions be made about rationing of limited, life-sustaining resources?

- explain exercise to full group (5 minutes)
- individuals conduct exercise (30 minutes)
- discuss exercise in small groups at tables (25 minutes)

Notes: individuals will complete the Q-sort exercise independently followed by group discussion at the table. The small groups will be asked to 1) come to agreement on top 3 most acceptable statements and 3 least acceptable statements from the exercise. 2) identify other areas of convergence and any divergent views

11:40 Plenary Discussion of Q-Sort Experience

Facilitated full-group discussion of exercise, highlights and outcomes

12:00 pm Lunch Break

12:30 pm Plenary Overview of Small Group (World Café) Discussions

12:40 pm Small Group Discussion Vignettes

Goal: To allow participants to consider a suite of vignettes in small group conversations. Vignettes will present issues that people can personalize. Individuals will be asked to consider priorities and make recommendations regarding altered standards of care and allocation of limited resources under hypothetical scenarios.

Steps: Using a “World Café” style process, participants will move through a suite of vignettes in small groups. Each individual will move through three different small groups to address all three of the following topics:

- What should be the goal of altered standards of care?
- Should altered standards of care be standardized?

Individuals will be asked to move from one vignette to another in 30 minute intervals (with 5 minutes between). Each group will be asked to build on the previous group as part of a progressive conversation that integrates the ideas of all perspectives into a coherent outcome. Furthermore, individuals will carry the thinking from one group into other conversations. Individuals move through the tables/ vignettes independently thereby mixing the range of perspectives that interact in the groups. Three vignettes will be addressed by each individual. 8 or 10 people will be targeted for each group size.

The job of the facilitator is to welcome people, explain the purpose and manage a quick-paced conversation. After the first group, the facilitators will share the essence of previous conversations with the next group so they can build on it.

Worksheet: A worksheet will be provided in packets for each facilitator to help them move the group through the vignette, draw clear conclusions, and merge the discussions of each group. A set of questions will be offered to focus the conversation and help capture outcomes. For example, the groups could be asked to consider the following factors relative to the specific vignette:

- Principles - What principles that guide decision making?
- Checks & Balances - Is there any obligation to make sure what we're doing is right?
- Is anything a deal breaker - absolutely taboo?

Outcome: Conversations will be facilitated to help move the groups toward recommendations.

2:15 pm Break

2:30-3:00 Revisit Q-Sort in Small Groups

Participants will review their original Q-sort will be able to make any changes they want based on the discussions they have been having throughout the day. Each table will try to come to consensus on the most important and least important statements with room for dissent. Consensus may not be possible.

3:00 pm Plenary Discussion

Return to the full group for a facilitated discussion of the outcomes from the small group sessions. Identify, as a full group, if possible, the “Most Acceptable” Q-statements and the “Least Acceptable” Q-statements from the entire participant group.

3:30 pm Closing and Discussion of Follow-up

3:45 pm **Post Evaluations**

4:00 pm **Adjourn**

2. Background Information on Healthcare Decisions in Disasters

As background, a presentation on Healthcare decisions in disasters was provided. Characteristics relevant to emergency medical response and healthcare systems; how disasters can impact healthcare systems and some of the types of decisions that need to be made about access to scarce, lifesaving resources were explained.

It was noted that there is no extra capacity in the United States health care system. King County has 18 hospitals with 3,700 beds. Most hospital beds are occupied all the time and two-thirds of intensive care unit beds are in used on any given day. In the event of a pandemic, or other natural or human caused disaster, hospitals would quickly become overwhelmed with patients. Natural or human-caused disasters can compound the current limits on health care systems by damaging or destroying health care facilities. Disasters can also impede health care providers from reaching their places of employment due to injury or illness.

Based on models for pandemic flu under the worst case scenario, i.e., the 1918 Spanish flu, one-third of King County's population or 570,000 people would fall ill, one-half of the infected population would need medical attention, nearly 60,000 would need to be hospitalized but only 2% would die. Consequently, health care resources would quickly become limited. For example, in the Intensive Care Unit (ICU) where the most severely ill people would be treated, many patients will require a ventilator. The number of ventilators needed would far exceed the equipment available. In addition, many people, due to limited health care resources, would have to be cared for in their home.

Everyday, health care decisions are made by family, health care providers, insurance companies and others on what type of treatment a patient receives, where the patient is treated and by whom. In a disaster like pandemic flu when resources are scarce, many questions arise to decide if the current system should be changed and, if so, how would the changes affect the system. Because of the scarcity of resources and the limitation on facilities and providers, decisions must be made on the best uses of available resources. So, questions may also arise to determine who should be given priority to use life sustaining treatment like ventilators and what factors should be taken into consideration when making the decision.

Some of the questions covered during the public engagement process included:

- Should the current standard of first come first served be used during a disaster?
- Should medical treatment be reserved for those most ill?
- Should care be prioritized based on age?
- Should resources be limited to those most likely to survive their illness?
- Should one's job be a factor in receiving treatment?
- Should all doctors and hospitals be expected to follow the same rules for care and treatment?

Since resources are not limited at this time, health care providers are not required to make the types of decisions that were being discussed. During a disaster like a pandemic or an earthquake, resources will be inadequate to meet the demand. The purpose of this meeting was to get the public's input on these health care decisions during disasters.

3. Q-Sort Statements

1. People with disabilities should be given priority for medical care.
2. People without transportation should be given priority for medical care. It may take them a lot longer just to get to the hospital and then they will be at the end of the line.
3. People shouldn't be given priority for medical care if they are expected to survive, but will require a caregiver to get through everyday life.
4. You have to save the greatest number of people, even if it means that some people aren't going to be treated and will die.
5. Making sure decisions are fair is more important than getting people treated as quickly as possible.
6. People should be given medical care on a first come, first serve basis. People should be treated in the order they arrive in the hospital.
7. How someone survives is important. People shouldn't be given priority if they are going to survive but be in a coma.
8. It's a better use of medical resources to help the most people even if we can't give the same level of care as we could in non-emergencies.
9. If more people in a specific age group are getting sick and dying from a pandemic flu, then that age group should get priority for medical care.
10. Doctors, nurses and medical workers should get priority for medical care because they are risking their lives to treat sick patients.
11. Doctors, nurses & medical workers should be given priority for medical care as an incentive to show up for work when they may be worried about catching the flu.
12. Doctors, nurses, and medical workers should have priority for medical care because they can help everyone else when they recover.
13. People who do not speak English very well have greater difficulty accessing the health care system so they should be given priority for medical care.
14. Parents and caregivers should be given priority for medical care so there's someone to take care of the children, elderly, and disabled.
15. People who can afford to pay should be given priority for medical care.
16. The elderly should be given priority for medical care.
17. We need to preserve all of our generations, not just one particular age group.
18. Young adults should be given priority for medical care.
19. Children should be given priority for medical care.
20. Give priority for medical care to the patients with the best chance of survival. Otherwise, it's not the best use of resources.
21. Poor people have greater difficulty accessing the health care system so they should be given priority for medical care.
22. Priority for medical care should be given to patients expected to live the longest.
23. Patients should be randomly selected for medical care because it is too difficult to figure out a fair way to give anyone priority.
24. In a flu pandemic, getting people treated quickly is more important than making sure it is fair.
25. First responders (firefighters, police, ambulance workers) should have priority for medical care because they are important to everyone's safety.
26. It is important to give priority to certain groups. Otherwise, the hospital will fill up with people who get there first and those who get sick later may not get medical care
27. Pregnant women should be given priority for medical care.

4. World Café Vignette Details

Small groups of eight were asked to consider a series of hypothetical scenarios or "vignettes" intended to help participants to personalize the kind of decisions that will need to be made in the case of an influenza or other severe pandemic. Using a "World Café" style process, participants moved through a suite of 3 vignettes in small

groups. Each group was asked to build on the discussion of the previous group as part of a progressive conversation that integrates the ideas of all perspectives into a coherent outcome. Groups were asked to carry the thinking from previous group into their conversations. The following summary provides high-level summaries of the scenarios.

A. Vignette 1

Scenario

Critically ill patients are flooding the emergency department at General Hospital during the peak of an influenza pandemic. The Intensive Care Unit (ICU), where the most ill patients get treatment, is full. General Hospital has even fewer staff than usual, due to the illnesses among the doctors, nurses, and other workers. Those who are at work are fatigued from long hours.

There are 75 patients in need of lifesaving care in the Intensive Care Unit (ICU). The hospital staff have exhausted all of their options and have stretched all medical resources and staff to their limits. The first five of these patients to arrive have severe cases of the flu and need life-saving care in the ICU. If they can get care in the ICU, they all have an equal likelihood of surviving. If not, they will most likely die.

- Patient A: a 15-year-old male high school student
- Patient B: a 34-year-old restaurant cook, father of three young children. He is an immigrant and his family did not know whether he could get treatment without health insurance, so they delayed bringing him to the hospital.
- Patient C: a 23-year-old male police officer. He is single with no children.
- Patient D: a 58-year-old female nurse who became infected with the flu while caring for sick patients. She is married with grown children.
- Patient E: a 78-year-old female retiree. She is married to man with advanced Alzheimer's dementia. She is his primary caretaker.

Question 1:

Two beds in the ICU just became available. How should the hospital staff determine who should get the beds? Why?

Question 2:

Do you think it's a reasonable expectation that hospital staff can make decisions in real-time about who should get treatment based on age or their role in society (such as being a caregiver or a health care worker)? Why or why not?

Question 3:

Suppose that the pandemic is now over. Here is what happened to the patients:

- Patient A: a 15-year-old male high school student: Despite best attempts to treat him in the ICU, the teen developed a lung infection and died three weeks later.
- Patient B: a 34-year-old restaurant cook: He needs to be in the ICU for a month, but has a full recovery from the pandemic flu.
- Patient C: a 23-year-old male police officer: He has a full recovery from the pandemic flu. Six years later, he dies while on the job.
- Patient D: a 58-year-old female nurse: Her recovery is a long one. By the time she is able to go back to work, the pandemic is over.
- Patient E: a 78-year-old female retiree: She needs to be in the ICU for a month. She recovers from the pandemic flu and lives to be 89.

Now that you know the outcomes, does it change how you feel about who should have priority? Would you do it the same way?

B. Vignette 2

During a pandemic, there are over 50 patients in need of lifesaving care in the Intensive Care Unit (ICU) of a local hospital. The hospital staff have exhausted all of their options and have stretched all medical resources and staff to their limits. You need to decide who will get the ICU beds among the first four of these patients to arrive at the hospital. With treatment in the ICU, all are equally expected to survive, but without ICU treatment, any one of them could die.

- Patient A: 3-year-old child with severe flu
- Patient B: 30-year-old pregnant woman with severe flu
- Patient C: 17-year-old high school student who has been in a car accident
- Patient D: 80-year-old woman with severe flu

Question 1:

How would you prioritize the patients for treatment if you only have two ICU beds available? Why?

Question 2:

What if you knew more about their health and survival prospects if they get treatment. Would it make a difference if you knew the following?

- Patient A: The 3-year-old child has a heart condition. Even with treatment in the ICU, he has about a 40% chance of surviving.
- Patient B: The 30-year-old pregnant woman has about a 75% chance of surviving if treated in the ICU. If her baby survives, it may have developmental disabilities.
- Patient C: The 17-year-old high school student is already in a state of severe trauma. If treated in the ICU, he will most likely survive but be in a long-term coma.
- Patient D: The 80-year-old woman is expected to survive if treated in the ICU

Question 3:

Suppose that Patient D (the 80-year-old woman) did not get priority for treatment at General Hospital so her family took her to a different hospital in the same county where she was given priority for treatment. Do you think it's a fair system if the hospitals across the county do not have the same decision-making procedures?

Question 4:

What could be problems with inconsistent decision-making procedures?

Question 5:

What are advantages to having more flexibility for hospitals to make their own decisions?

Question 6:

What if priorities for treatment were consistent across the state, but Patient D's family flew her to a hospital across the state where she could qualify for a priority group and get immediate treatment? Is that fair?

C. Vignette 3

In a hospital's Intensive Care Unit (ICU), all the ventilator machines that make it possible for critically ill patients to breathe are in use during a severe pandemic. A ten-year-old child has been brought to the hospital with severe breathing problems due to the flu. If he doesn't get a ventilator soon, he will likely die. Note: the actions described here are not based on any actual guidelines or planning by any hospital—these are hypothetical situations.

There is a 68-year-old man on a ventilator now. The hospital staff decides that this patient should be taken off the ventilator and the ventilator should be given to the incoming child patient.

Question 1:

Do you agree with their decision? Why or why not?

Question 2:

There is a 40-year-old patient who is on a ventilator now. He has the same chance of survival as the ten-year-old if he stays on the ventilator. The hospital staff decides that this patient should be taken off the ventilator and it should be given to the incoming child patient. Do you agree with this guideline? Why or why not?

Question 3:

What if you knew that the ten-year-old's predicted chance of surviving, even with the ventilator, is 40% and the 40-year-old's predicted chance of surviving is 75%? Does that make a difference?

Question 4:

There is a 33-year-old emergency room doctor who is on a ventilator now. Her prospects for surviving are good if she stays on the ventilator for one month. The hospital staff decides to take her off the ventilator and give it to the incoming child because the child has more years of life left if he survives. Also, he probably won't need to stay on the ventilator for more than two weeks, so it will be available for another patient sooner. Do you agree with their decision? Why or why not?

Question 5:

Suppose Hospital A is a large urban medical center with a large Intensive Care Unit (ICU), a large staff, and many other medical resources. It also serves a very large population. Hospital B is a small, rural facility in the same county with no ICU, a small staff, and far fewer resources. It serves a small population base. Under ordinary circumstances, people from the rural area travel to Hospital A when they need a higher level of care. Hospital A, which has more staff time available for planning, has done extensive preparedness planning for a pandemic, whereas Hospital B has done almost none. Now imagine that state guidelines mandate that hospitals share medical resources during an influenza pandemic. The reasoning behind the guidelines is that resources should be available in more rural areas so that care will be available closer to patients. A small number of ventilators from Hospital A must be sent to Hospital B, along with trained staff from Hospital A. Do you think this would be fair? Why or why not?

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