

**MINNESOTA PANDEMIC ETHICS PROJECT
SMALL GROUP DISCUSSION**

FACILITATOR/NOTE-TAKER GUIDE

Facilitation and note-taking roles:

- Preparation is key!
- Facilitators, you are in charge of keeping the small-group discussion flowing and on-topic. Please turn in any notes you happen to take during the small group discussions to supplement your note-taker's notes.
- Note-takers, you are in charge of capturing the discussion – what people recommend, what concerns them, and always why, why, why. Both of you are to be neutral and not offer your own opinions. ***Note-takers, think of yourselves as “co-facilitators” in a way, too. If you see that the group is stuck or has strayed off-topic, offer a suggestion. If you don't understand someone's comment, ask for clarification.***
 - **Laptops:** You are free to take notes by hand or on your own laptop.
 - If you prefer using your laptop, be vigilant about the power cord, and don't use it in a place that might trip someone. Tape the cord down with duct tape.
- Facilitators and note-takers, we will provide tablets on every table so that you have extra paper if needed. Pens are also provided.
- You are neutral for purposes of the discussions and should not offer opinions regarding the substance of the issues.
- Familiarize yourself with the two small group activities and the individual activity, the types of questions we anticipate and strategies for responding and moving the group discussion forward.
- Set the tone for your small group and make it a fun and inclusive event for everyone.
- Keep track of time in small group discussions. Remind people when the current conversation will end and intermittently let the group how much time remains.
- Be aware of the resources and support available to you:
 - Background on size of different age groups in MN (that might be relevant during the second exercise)
 - 3x5 cards on tables for capturing related questions/recommendations

Starting the small group process.

1. Make participants feel welcome. Thank them for coming.
2. Introduce yourself and the note taker and your respective roles.
3. **Note-taker: Explain that you are NOT writing down participants' names. You're taking notes about what gets said, not who says it.**
4. Have participants introduce themselves and answer an icebreaker. Ask them to keep their answers very short.
 - What is your name and where do you live?
 - Share something that you like to do for fun.

ACTIVITY 1: GUIDANCE FOR 1ST EVENING'S DISCUSSION OF RATIONING OBJECTIVES (approximately 1 hour, 5 min.)

1. Affirm that today's questions are unusual and challenging (intellectually and emotionally), and this is why the health department seeks broad public input before issuing guidance. If the answers were obvious, we would not be seeking input.
2. Stress the importance of hearing from everyone and respectfully listening to one another.
 - Remind participants that if you interrupt them, it is not because their point is unimportant but because we need to be sure to hear from everyone. Explain in advance that you might have to interrupt from time to time, not because someone's comment is unimportant, but because it's important that all have a chance to be heard.
 - Ask for (but do not force) responses from everyone at the table. Work at a friendly and crisp pace. Try to manage the conversation so that one or two voices do not dominate the discussion. If someone is talking a lot, don't be afraid to interject at a pause and say "Those are great comments – let's see what others think about this. Mary or John, do you have anything to add?" Use your own judgment about intervening little (if the group is conversing easily and well) or a lot (if the group is struggling or going off track).
 - Groups are free to come to agreement (and you may assist them to get there). However, consensus is not required, and opposing views do not have to be reconciled. It is more important that various perspectives and ideas are shared and heard within the group.
3. Ask WHY! This is one of the main objectives of the day to understand the WHYS. Emphasize the importance of sharing the reasons behind opinions. This will help everyone understand each other better. Ask what values and criteria people use to guide their answers. Probe for the underlying values, goals, interests, fears, hopes.
 - Urge the group to think about the best reasons why others ought to agree with them.
4. Paraphrasing, speaking in terms of underlying interests and values and giving synopses of the group process/decisions may prove helpful when people are frustrated or conflicting ideas arise.

- State the key themes you hear, including views held in common and issues seen differently around the table.

ACTIVITY 1: Potential distractions, strategies for staying on track and prompts

Focus on advising state leaders about rationing.

The entire day is about advising the state, not about making decisions within a family or neighborhood. Some participants might focus overmuch on personal decision-making.

Strategy:

PROMPT: I hear what you're saying about how you'd make a decision in your family. How would you apply that to advice for Minnesota's leaders?

Some people will be very creative in order to avoid rationing altogether.

Rationing is uncomfortable, and some participants may offer suggestions to avoid rationing, like "develop domestic manufacturing capacity," "increase stockpiles" or "use isolation and quarantine to prevent the spread of the disease."

Strategies for responding and moving the conversation along:

- The preliminary recommendations make clear that rationing is a last resort. The federal government is working to improve domestic manufacturing capacity of several resources, and both state and federal governments are stockpiling resources and planning for isolation and quarantine, just as examples of the breadth of pandemic planning that is ongoing. There's little controversy about the desire to avoid rationing, so let's not spend time on that.
- In a severe pandemic, no matter how much we plan in advance and work to control the disease's spread during the pandemic, shortages are inevitable. We're here to discuss these hard questions about rationing.
- Invite participants to write their suggestions on a 3x5 card.

Questions about the preliminary recommendations and the panel's thinking might arise.

We anticipate that some participants will want to know more about **what the panel considered, what they decided and why**. These questions could easily use up the limited time available.

Strategies for responding and moving conversation along:

- PROMPT: We are looking for fresh thinking: your opinions on what the objectives guiding rationing should be. We are here to hear what you say and why. You may identify things the panel did not.
- Suggest that participant write the question on a 3x5 card, pass it on to roamers. These questions will be addressed as the day goes on, as time permits.

Activity 1 (continued)

Implementation questions also might arise.

Strategies:

- PROMPT: Distinguish implementation questions from the values-related questions central to this project. If someone says they are opposed to a proposed objective, press to determine the sources of the objection. Why? Is it due to a difference in values or a concern about feasibility of implementation?
- PROMPT: Assuming the objective could be implemented, do you agree/disagree with the objective?
- Note-takers should capture implementation concerns/recommendations.
- Remind participants of the option to put implementation concerns/questions/recommendations on 3x5 cards.

Some people might want to suggest groups that should be “excluded.”

Strategies:

- PROMPT: The emphasis of this discussion is to get at who should come first, second and so on, not whether there are groups that should be excluded completely. Focusing on a “tail-end” of the rationing problem isn’t the most important aspect of the discussion.
- PROMPT: Ask for clarification: Are you saying that X Group should get no resources at all under any circumstances, or are you saying that X Group should be “de-prioritized” and receive resources later than other groups?
- Note-takers should capture “exclusion” concerns/recommendations.
- Remind participants of the option to put implementation concerns/questions/recommendations on 3x5 cards.

Key worker questions.

Some participants may want to discuss who should be included in the group of key workers. There are many other state and federal groups who are working on this topic and they are better suited to do so than the panel was, so the preliminary recommendations don’t go into much detail about who should count as a key worker.

Strategies:

- PROMPT: Given that you agree that worker group X should be included among key workers, protecting infrastructures is important to you.
- PROMPT: Do you think protecting the infrastructure is the only objective, or the most important objective, or are there others that Minnesota should attend to as well?
- PROMPT: Should Minnesota use scarce health resources only to protect us from infrastructure disruptions?
- PROMPT: Clarify whether the suggestion about key workers means that a new objective is being suggested.

Activity 1 (continued)

- Are you suggesting a new type of key worker because you see it as an important type of health care, public health or public safety worker? If yes, then write down the comment, but try to move the conversation along.
- Are you suggesting a new type of key worker because you think another objective needs to be added (e.g., economic stability, national defense)? If a new objective is being suggested, ask for group response.
- Here are some excerpts of the preliminary recommendations for this project. This might help if your group gets stuck on a key worker issue.
 - Minnesota’s preliminary recommendations define key workers as those whose functions are critical to limiting flu-related deaths or maintaining health care, public health, public safety and other critical infrastructures, including volunteers. Minnesota’s preliminary recommendations include a few more categories of workers than federal plans do, like child protection, day care, mortuary science and spiritual leaders.
 - The definition of “key workers for essential functions” will evolve as planning progresses and must be reassessed to fit the circumstances of an actual pandemic. Planners must balance the need for preserving infrastructures (which would tend to cause the key worker definition to expand) with meeting the needs of the general public (which would tend to cause the definition to contract).
 - The federal government estimates that about 4.5% of the population would qualify as key workers during a pandemic, amounting to approximately 210,000 workers in Minnesota. Most of these (150,000) are healthcare and emergency services workers whose jobs will be vital to controlling the pandemic. The remaining 60,000 are workers whose job functions are critical to keep society functioning.

Age issues

If the topic of age comes up, ask the person to write the comment down so that s/he doesn’t forget it. Age is such a large topic, that we have an entire discussion set aside for it. Ask participants to hold onto their thoughts about age until the issue comes up in the afternoon.

The agenda calls for completing Activity 1 during the first session, and then explaining what issues will be discussed the next evening (age-based rationing and discussing access and removal of barriers). If Activity 1 goes surprisingly quickly, go ahead and begin Activity 2 (age), but leave room for setting up the access/barriers discussion.

END OF SESSION ONE

BEGINNING OF SESSION TWO

ACTIVITY 2: GUIDANCE FOR THE AFTERNOON DISCUSSION ABOUT AGE

(approximately 40 min.)

When discussing age, remember the following:

- The main question isn't whether age is more important than risk of dying. It's whether age should be used to sort a group that is at the same risk of dying.
- Remind people that this is not about an individual grandpa sacrificing to give to grandchild or vice versa, it is about whether an entire age group or groups should be prioritized before others.
- Remind people that this sort of age-based rationing is different from considering age for clinical reasons. Currently some age groups are prioritized to receive annual flu vaccines, but the reasons are clinical. Usually it is because these groups are at particularly high risk of dying. In this small group discussion, we are assuming that different age groups will at times have equal risk of death.
- ADDITIONAL RESOURCE: You have a table of census data showing the size of various age groups in MN that might be helpful to the discussion.
- ADDITIONAL RESOURCE: You have an illustration of a W-shaped mortality curve to illustrate how different age groups can be at the same level of risk of dying.

PROMPTS

- Keep asking WHY or WHY NOT!
- If age isn't used, what is the alternative? WHY? Does the group favor distributing resources randomly (like with a lottery or coin flip). WHY? WHY NOT?
- When different age groups have equal risk of death from the flu, should MN look at age in and of itself for non-clinical reasons? If so, WHY? Because we need a certain age group? Because fairness requires it? For a combination of reasons?
- For those who find it hard to decide about whether or not to prioritize based on age, ask, "What makes it hard to decide?"
- Offer some possible age groups and ask, what about prioritizing:
 - Children under 18
 - Adults 18 – 40
 - Adults 41 – 65
 - Seniors 66 – 85
 - Seniors 86 and over
- Ask if there is a more appropriate age group that should be considered (like a bigger or smaller age range). WHY?

ACTIVITY 3: IMPROVING ACCESS AND REMOVING BARRIERS
(approx. 40 min.)

1. What kinds of problems can people in your community have getting access to care?

PROMPTS:

- At Courage Center consider rephrasing or adding “What kinds of problems can people with disabilities have getting access to care?”
- The notion of “community” in the question can be considered broadly or narrowly. Perhaps the most obvious is geographic (town, county, neighborhood), but it can also apply to other communities with which someone identifies (a particular racial or ethnic group; people with disabilities; people with low income, etc.)
- “Access to care” can also be consider broadly, to mean access to health care, access to needed medicine or vaccines,
- Examples could include lack of insurance coverage, poor availability of care in the neighborhood, transportation issues, cultural concerns (including distrust of health care providers or government public health and/or fear of discrimination)
- Barriers can be physical (like travel distance or being home- or bed-bound), financial, cultural, or even legal (e.g., barriers faced by undocumented workers). They can be real or perceived.

2. Specifically, what types of things can the state try to do to improve access to care?

PROMPTS:

- Remove cost as a barrier: provide resources for free or without regard to insurance status
 - What kind of resources? Is there a limit? Vaccines? Antiviral drugs? All pandemic flu-related health care including hospitalization assuming hospital beds are available?
- If distrust is a concern, how can trust be enhanced?
 - Are there particular organizations or groups in your community that you’d recommend that the public health department work with?
- Transportation?
 - How far is it reasonable to ask someone to travel to get vaccinated? To get

medicine for a sick person?

- Should home delivery of medicine for sick people be expected and prioritized during planning? Is it reasonable to expect home delivery?
- Do you think that it is likely that enough volunteers would be available to run errands, including filling prescriptions, for sick people?

3. What steps can be taken to promote fairness among all groups of people, including those of us who lack good access to care during a flu pandemic?

- Since activity one's discussion should already have elicited conversation about fairness in rationing generally, this question should get more into questions about fairness in terms of access to care/health resources.

PROMPTS

- What should we expect in terms of fairness? What are the limitations, the constraints?
- What does it mean to be "fair"? Fairness can mean exact equal treatment (e.g., everyone pays the same amount; or everyone gets it free; everyone travels the same distance). Fairness can mean equalizing opportunity and burden (e.g., people pay on a sliding scale; those who need transportation assistance get it, but those who don't need it don't.)

ACTIVITY 4: GUIDANCE FOR THE INDIVIDUAL “PAPER DOLL” ACTIVITY AND CONCLUDING DISCUSSION

(approximately 30 min.)

See your worksheet. There are no additional instructions, discussion guides or prompts. **NOTE THAT WE HAVE ADDED A DISCUSSION QUESTION – IN CONTRAST TO DULUTH, WE’RE NOW ASKING PARTICIPANTS TO SHARE HOW THEY ORDERED THE SLIDES AND EXPLAIN WHY.** If someone wants to re-order their cards (cross out and re-number) after discussion, that’s fine. Be sure to collect the numbered sets of cards.

FINAL AGENDA ITEM: Final thoughts/further concerns of participants

This is an open-ended opportunity for participants to ask questions or raise concerns regarding pandemic planning that they’d like MDH to hear. We’re not promising that anything that gets mentioned will be acted upon, because our project is limited to ethical concerns about rationing. That said, if they have other suggestions – either about rationing or about planning more generally, we’re happy to funnel their ideas back to MDH.

Be sure to thank the participants, local partner, and any other presenters who may have participated. Explain that participants should watch the project website for results/final recommendations.