DIVERSITY DECISION MAP (DDM) USER GUIDE: Conducting Stakeholder Discussions Using the DDM

STAKEHOLDER DISCUSSION SETTING AND MATERIALS

PARTICIPANTS

Two facilitators familiar with the DDM and illustrative examples

Participants: Ideally, full group should be fewer than 40. Breakout groups should be 4-5 participants. Groups should include a mix of different stakeholders, including but not limited to:

- Community representatives
- Patient representatives
- Study investigators
- Research and study staff
- Ethics, IRB, and/or regulatory staff
- Institutional staff involved in research operations, technology, and systems
- Institutional staff involved in patient and/or community engagement

MATERIALS

- Prep Work: DDM Demonstration: view video recording titled "Diversity Decision Map Community Engagement Animation"
 - Uses map to walk through one approach to Community Engagement, upstream inputs and downstream consequences
- DDM Introduction (recording): Data Collection Example
 - Describes two different approaches to measure selection and traces alternate pathways with different tradeoffs/consequences
- Glossary sheet (printable)
- Diversity Decision Map: large format image (printable)

• This User Guide or separate Discussion Prompts (both printable)

SAMPLE AGENDA FOR STAKEHOLDER DISCUSSION

Prep Work:	DDM Demonstration: Stakeholders review the	DDM Community
15 minutes	"Diversity Decision Map Community Engagement	Engagement Animation
	Animation" video	video (11 minutes) <u>link</u>
Timing: 2	Component	Materials/Activity
hrs total		
10 minutes	Introduction: Facilitators begin the meeting.	
	Members introduce themselves. Those who are	
	convening the stakeholder discussion describe the	
	study, research issues, decisions, or questions to be	
	discussed.	
25 minutes	DDM Introduction video presentation: Facilitators	Introduction
	play intro video that will:	presentation video
	Define key terms	(link)
	Introduce the DDM	
	 Walk through an example on <u>Data</u> 	
	<u>Collection</u> that demonstrates how upstream	
	decisions inform downstream	
	constraints/opportunities along two	
	different paths.	
	Note built-in pauses in video for facilitators	
	to take participant questions.	
50 minutes	Small Group Discussion (depending on number of	
	participants):	OPTIONAL
	<u>Option A if group numbers 7 or less</u> : The whole	 Glossary handout
	group selects which node(s) on the DDM to	 DDM large format
	discuss, based on stakeholder focus.	image/handout
	Option B if group numbers 8 or more:	 Discussion
	Facilitators assign different decision nodes to	Prompts/handout
	each small group <u>.</u>	Highlighters, pens
	Break out into small groups. Following the prompts,	 Sticky notes
	each group maps downstream consequences of a	
	decision point informed by prioritizing diversity.	
	(See below for detailed Discussion Prompts.)	
	Orientation to the DDM: 10 minutes	
	Apply the DDM: 20 minutes	

	 Identify Decision Pathways & Tradeoffs: 20 minutes 	
35 minutes	Debrief: Instructors review upstream influence, downstream consequences, identified tradeoffs (see prompts)	DDM image

SAMPLE DISCUSSION PROMPTS

SMALL GROUP DISCUSSION (50 MINUTES)

ORIENTATION TO THE DDM (10 MINUTES)

- What stage is the research in right now? Base discussion on focus of stakeholder engagement OR the assigned decision node.
- Identify connected research activities/decision nodes: What were the decisions made in previous stages? What impacts do they have on our current stage?
- What options at the current stage remain open, and what have been closed off, due to previous decisions?

APPLY THE DDM (20 MINUTES)

- Identify a decision-making point or 'fork in the road' to discuss. Consider at least two different options or pathways.
- Identify other important nodes and research stages to examine: What are important downstream consequences that must be considered? Locate them on the DDM.
- Trace pathways between the current stage and those identified as important to examine, by systematically walking through the different paths connecting those boxes: How would this decision impact those areas?
- To generate discussion of unanticipated consequences, trace each pathway to and through at least one other research activity or stage not yet discussed (e.g., a box that is perhaps thought to be indirectly connected or located further downstream).
- Identify nodes on the DDM that have not yet been invoked or discussed. Trace possible pathways between decisions made in the current research

stage to the activities of these other nodes, to determine whether there are additional downstream consequences that are unintended.

IDENTIFY DECISION PATHWAYS & TRADEOFFS (20 MINUTES)

Within the small group, articulate the benefits/drawbacks of each path and why one path is preferable, OR what additional information is needed to finalize a decision. Prepare to report back to larger group. Consider:

- How do the currently available options impact diversity of participants, inclusionary practices in the research, prospects that the research can advance equity, etc.?
- How would possible tradeoffs (e.g., in response to resource constraints, study parameters, funder requirements, etc.) impact the selected decision node in terms of goals related to diversity? To inclusion? To equity?
- Think iteratively: Can you redirect upstream decisions to prioritize goals of diversity, equity and inclusion?
 - What paths were NOT taken that impacted the current decision node?
- Will current decisions and tradeoffs compound as barriers or facilitators in later decision nodes?

DEBRIEF (35 MINUTES)

Return to large group. A participant from each small group explains the decision/decision node they discussed and the tradeoffs they identified. For the large group discussion, facilitators will prompt participants to consider:

What different pathways going forward were identified? What potential advantages, consequences, and tradeoffs were identified for each pathway?

What questions still remain? Are there pathways that have not been explored, but should be? Are there upstream decisions that could be reversed, that would open up new or alternative options downstream for diversity and equity?

Have all the relevant and affected stakeholders been involved in the discussions? What additional steps need to be taken to ensure meaningful engagement and multi-stakeholder discussion? What are the next steps for decision-making? Who has the authority to make decisions, and how will the stakeholder discussion be incorporated into their decision-making process? How will stakeholders be notified of decisions and whether and how their discussions impacted that process?

DDM EXERCISE HANDOUT

Group(s) will have about 50 minutes to apply the DDM to a particular decision point they identify. This may be hypothetical or directly related to a proposed or ongoing research project. Be sure to have the full DDM image displayed/available.

Timing: 50	Activity	Prompts
minutes		
total		
10 minutes	Orientation to the DDM Base discussion on the focus of the stakeholder engagement OR the assigned decision node. Identify it on the DDM.,.	 What stage is the research in right now? Identify connected research activities/decision nodes: What were the decisions made in previous stages? What impacts do they have on the current stage?
20 minutes	Apply the DDM Identify decision-making point to discuss: describe at least two different options (e.g., A or B)	 Identify other important research nodes and stages to examine: How would this decision impact these areas? Trace different pathways connecting <u>at</u> <u>least two</u> research activities or boxes. Trace each pathway to and through at least one other research activity or stage not yet discussed (e.g., a box that is indirectly connected or located further downstream).
20 minutes	Identify Decision Pathways & Tradeoffs Within the group, articulate the benefits/drawbacks of each path. Prepare to report back to larger group.	 What are the implications of one path vs. the other, for diversity of participants, inclusionary practices in the research, prospects that the research can advance equity, etc.? Can upstream decisions be redirected to prioritize goals of diversity, equity and inclusion? What paths were NOT taken that impacted the current decision node?

Diversity Decision Map



GLOSSARY

Consortium: a group of studies that are organized under a larger research effort.

Data Aggregation: where data from one study can be combined with data from other studies, to create a big dataset that can be analyzed.

Decision Node: a highlighted research lifecourse stage where specific decisions arise that are informed by upstream factors and can have cascading, downstream impacts. There may be a choice between two options, or a range of potential paths to follow. Our map highlights a particular research lifecourse stage where we have identified a decision node based on our data.

Diversity: In the Ethics of Inclusion Study, and in the Diversity Decision Map, we do not provide a specific definition of diversity. Instead, we are interested in how different PMR stakeholders define "diversity," for particular research studies. Additionally, we are interested in whether the

DIVERSITY DECISION MAP: USER GUIDE

Diversity Decision Map could be one tool to help stakeholders explore and discuss the questions of "what kinds of diversity?" and "what is diversity for?" in PMR studies.

<u>Harmonization</u>: the process of combining data from different studies to make data from one study comparable to/with data from other studies.

<u>Measures</u>: the ways and types of data researchers collect about participant characteristics, such as income, age, and religious background, through specific questionnaires (or "instruments") or kinds of variables (for example, age can be measured in years, child vs. adult, or by age group).

Precision Medicine Research (PMR): PMR combines a broad spectrum of individual data from different sources to identify risks and treatments that are more effective for individual patients. These data can include genetic information, patient history, lab tests, health record data, and self reported data about health behaviors and physical environment. They can be collected through your visits with your healthcare providers and also other ways, such as information from wearables like fitbits. These data make up large datasets that are used in research and are often referred to as "big data."

<u>Research Lifecourse Stage</u>: different activities that a research study undertakes, such as Recruitment, Retention, Data Collection and Data Analysis.

<u>**Tradeoff**</u>: When researchers confront a decision node, they may consider the tradeoffs, or the pros and cons, of taking one approach versus another based on a variety of factors, including their research study aims, prioritizing diversity, or institutional or resource constraints.

Upstream/Downstream: We use this language to talk about the impact of decisions on other research lifecourse stages; how decisions about diversity made in one moment are shaped by decisions that were made previously, upstream and earlier in time. Also, a decision has downstream consequences for what options relevant for diversity are available at a later time.



