

Appendix 1. Workbook instructions, questions and activities

Facilitator Instructions

Throughout the meeting, we will break into small group or Table Talk discussions. As the facilitator of these discussions your job will be to:

1. Set the time frame and define the tasks.
2. Lead and manage the group activities at the tables.
3. Lead the discussion and report the outcomes, conclusions, or decisions of the table to the entire group.
4. Record the table discussion, conclusions, or decisions of the table in the facilitator's workbook. Participants will record their individual responses in the participant workbook.
5. Keep the table group focused and on task.

The Table Talk sessions should allow everyone the opportunity to express their opinion. The purpose of the session is not necessarily to arrive at consensus, but to engage in a dialogue about the topic where all opinions are valued and respected. Some ground rules for a good dialogue include:

1. Use "I" statements instead of "we" or "you" or "they".
2. Listen actively. Avoid interrupting.
3. Share the airtime.
4. Use considerate language. Avoid using labels.
5. Feel free to pass if you are not ready or willing to speak. Don't pressure others to speak.
6. Confront misperceptions and mistaken ideas without accusing others.
7. Explore areas of disagreement and search for common ground.
8. Inquire rather than assume you know.
9. Be open to changing your mind.
10. Respect confidentiality.

Being an effective table facilitator may mean suppressing some of your own opinions in favor of the group process. The facilitator's role is to bring out the opinions of the group. Some guidelines for effective facilitation include:

1. Stay out of the content and refrain from giving your own ideas or opinions. There will be content experts available in the room. If someone at the table has a factual question, refer to one of the Town Hall moderators.
2. Avoid paraphrasing, especially during divergence. It can sometimes lead others to think their words are being manipulated. Ask participants to condense or reframe their response.
3. Keep the group focused and on task. Intervene if the group becomes tangential or undisciplined. Intervene if a participant becomes disruptive.
4. Pay attention to the needs of the group and the interrelationships of its members. Try to establish positive group norms early in the process.
5. Be prepared to resolve any developing problems. If conflict arises, deal with it an open and positive way.
6. Try to keep your own biases out of the process.
7. Stay on the sidelines as much as possible. If the group functions well, there is little need for intervention.
8. Try to be playful and make the process fun.

NOTE: At each table discussion, please write down what are clearly the important points people raised during the discussion. Examples would include things like, pros and cons, points people feel very passionate about, questions people raise that don't have direct answers, etc.

TELL US ABOUT YOURSELF.

Please mark the responses that best describe you.

1. What is your age?

- < 25 26-35 36-45 46-55 > 55
-

2. Are you....?

- African American
 - Arab or Arab-American
 - Asian or Pacific Islander (Please specify)
 - Hispanic
 - Native American
 - White, not Hispanic
 - Other
-

3. Do you have children?

- Yes No Well, they're not exactly my children but I treat them as my own.
-

4. Were you born in Michigan after 1984 or do you have a child in the household that was born in Michigan after 1984?

- Yes No
-

5. How much formal education do you have?

- High School or less Some or full college Graduate School
-

6. Have you ever donated blood to the Red Cross or for medical use?

- Yes No I don't remember
-

7. Are you an organ donor?

- Yes No Not Sure
-

8. Overall, how would you rate your health:

- Excellent Very good Fair Not so hot Poor

ACTIVITY 1

HOW DO YOU FEEL ABOUT THE BIOTRUST NOW?

How do you feel about having your or your child's blood spot in the BioTrust? If you (or your child) do not have a blood spot in the BioTrust, please let us know how you feel about this issue in general.

Circle ALL that apply to you:

- a. Neither my child nor I has a blood spot in the BioTrust
- b. Neutral
- c. Curious
- d. Fearful
- e. Hopeful
- f. Angry
- g. Suspicious
- h. Excited
- i. Eager to learn more
- j. Wish I had known about this sooner
- k. Positive
- l. Negative
- m. Other, please explain: _____

Any other thoughts on this?

ACTIVITY 2
BENEFITS AND CONCERNS

Possible Benefits

Please list five (5) possible benefits of the Michigan BioTrust for Health

	Benefits	To Whom
1.	<hr/> <hr/>	<hr/> <hr/>
2.	<hr/> <hr/>	<hr/> <hr/>
3.	<hr/> <hr/>	<hr/> <hr/>
4.	<hr/> <hr/>	<hr/> <hr/>
5.	<hr/> <hr/>	<hr/> <hr/>

Other comments:

Possible Concerns

Please list five (5) possible concerns about the Michigan BioTrust for Health

Concerns	To Whom
1. _____	_____
2. _____	_____
3. _____	_____
4. _____	_____
5. _____	_____
_____	_____

Other comments:

ACTIVITY 3

TYPES OF RESEARCH

Do you think that the blood spots cards should be used for research on the following?

- High Blood Pressure
 - Diabetes (Type II)
 - Mental illness
 - Depression
 - Alcoholism/drug addiction
 - Environmental Toxins (lead, mercury)
 - Heart Disease
 - Asthma
 - Breast Cancer
 - Learning disabilities
 - Obesity
 - Genetic Studies (childhood diabetes)
 - Childhood Diabetes
 - Arthritis
- What other conditions do you think should be researched using the blood spot cards?

List your top three YES votes:

1. _____
2. _____
3. _____

List your top three NO votes:

1. _____
2. _____
3. _____

Discussion

ACTIVITY 4

Who will have access? Who would you allow?

- **Researchers at the Michigan Department of Community Health (MDCH)?**
- **Researchers at Academic institutions?**
- **Industry researchers?**
- **All other researchers?**

Questions

1. Based on what you know today, do you or your child have a bloodspot in the BioTrust?

- Yes No I don't know

2. Who would you allow to have access to these bloodspots?

Researchers at the Michigan Department of Community Health?

- Yes No Not sure

Researchers at Academic Institutions?

- Yes No Not sure

Industry Researchers?

- Yes No Not sure

All other researchers?

- Yes No Not sure

Comments?

ACTIVITY 5 THINKING MORE ABOUT PERMISSIONS

First, a quick question:

1. Parents should be able to make decisions or set permissions on the research done using their child's bloodspots.

- Strongly agree Agree Disagree Strongly disagree

2. Would you give researchers permission to use your (or your child's) bloodspot?

- Yes – they can use my bloodspot and related health data.
 Yes – but only for my bloodspot.
 Maybe – ask me before you use it.
 No – Prohibit researchers from using my bloodspot.

3. Would you ever want a researcher to contact you?

- Yes – Allow researchers to contact me directly.
 Notify me first, so I can decide then.
 No—Prohibit all contact.

Are these options important to you? Why or why not?

ACTIVITY 6

IF YOU RULED THE WORLD FOR A DAY

If you ruled the world for a day, what policy/policies would you establish for the use of the bloodspots in the Michigan BioTrust for Health?

What kind of informed consent process would you like to see in place?

- Ask me first
- Ask me each time
- Opt in
- Opt out
- Blanket consent
- Online
- E-mail
- Mail

Any other things you have thought about?

ACTIVITY 7
COMMUNITY MEETING EVALUATION

1. Do you feel that the material was presented in a clear and accessible fashion?
 Yes No Somewhat
2. Did you find the videos clear and easy to understand?
 Yes No Somewhat
3. How well do you feel that you understand the Michigan BioTrust for Health?
 Very well Somewhat Not at all
4. Do you feel like you know where to go to get more information about the Michigan BioTrust for Health?
 Yes No Unsure
5. Did you feel that there were enough opportunities to express your comments, questions and concerns, either in discussion, with the clickers or the workbooks?
 Yes No Somewhat
6. Do you feel that your community's concerns and values were reflected in the discussion today?
 Yes No Somewhat
7. Do you have any suggestions for how we could improve these meetings?

Generally, do you agree or disagree with the following statements?

8. Using blood spots for research is a good idea.
 Strongly Agree Agree Disagree Strongly Disagree
9. Parental consent to have blood spots stored for possible research should **NOT** be required.
 Strongly Agree Agree Disagree Strongly Disagree
10. Parents should be able to decline having their baby's blood stored for use in research.
 Strongly Agree Agree Disagree Strongly Disagree
11. The bloodspots of all babies should be stored for possible research.
 Strongly Agree Agree Disagree Strongly Disagree

12. If my bloodspots, or my child's bloodspots, were in the BioTrust, I would want to be asked each time before it was used for research.
- Strongly Agree Agree Disagree Strongly Disagree
13. Assume your blood spots, or your child's blood spots, are in the BioTrust. Which would you prefer?
- They should be destroyed immediately
 They should remain in the BioTrust
 I should be asked permission for them to remain in the BioTrust
14. What is your greatest hope for the BioTrust as you see it now?
15. What is your greatest concern about the BioTrust as you see it now?
16. What other questions do you have about the Michigan BioTrust for Health?

**THANK YOU FOR YOUR PARTICIPATION IN THIS MEETING and COMMUNITY
ENGAGEMENT PROJECT**