Appendix 2. Exemplary Quotes Expressing Major Themes from Community Meetings Discussing the Michigan BioTrust for Health

Theme	Subtheme	Example/s
I. Public Awareness	*a. Baseline awareness*	-Why are we just now learning about bloodspots? (Flint, African American, F) -I never knew this existed until now. (Grand Rapids, N/A M) -Massive numbers of people need to be educated about this. (Grand Rapids, Asian-American, M)
	b. Ongoing communication	-How can the public be kept informed as to what is being researched, when it's being researched, and what the results of the research are at any given time? (Detroit, African American, F) -I am torn whether I should consent to it or not because I don't always know what is happening with mine and my kid's blood samples. (Detroit, Hispanic, F) -If it was my or my child's spot specifically for a certain research project aimed at a particular genetic indicator, I'd like to know and how my or my child's spot assists the research. (Ann Arbor, White, F)
	c. Accessibility of information	-More information should be presented in other media, (TV, radio), in multiple languages. (Detroit, translated from Spanish, Hispanic, M)
	d. Transparency and trust (See IX)	-Why was I never informed? I feel like they are doing or were doing something shady… (Flint, N/A, F) -Communication is key. If you're not staying informative, people will assume you're hiding something. (Ann Arbor, White, M)
II. Consent	*a. Affirming the principle of informed consent (e.g., the right to know)*	-People have the right to know. (Flint, White, F) -I believe the hospital should have the mother's consent, and let the mother know what's going on because she has a right to know! (Detroit, Hispanic, F) -Always allow the public to have the right to know everything about the research. (Grand Rapids, Asian-American, M) -Inform me if they still have it. I'm very interested in what my child's blood is for. (Flint, African-American, F) -I would like notification if my child's sample is used. (Jackson, White, F)
	b. Ask permission (opt in)	-If I ruled the world for the day my policy would be to inform the community about the use of bloodspots. Get consent first! (Detroit, African-American, F) -Being asked permission for use helps people feel more involved. (Detroit, African-American, F)
	c. Recommendations for legacy spots: Ask permission (opt in); start fresh (destroy legacy spots); or opt-out only (status quo)	-If a request comes in for bloodspots from 1984 to 2010, ask the permission of the people involved. (Petoskey, White, F) -Permission should still be obtained if possible. To use these bloodspots without the public's knowledge raises the issue of trust. (Petoskey, White, F) -In the coming year 2011, you have to obtain consent. Why not just destroy the old bloodspots? (Detroit, African-American, F) -For spots predating 2010, either seek consent or throw them out and start over with the spots that have given consent. (Ann Arbor, White, F) -If consent isn't given, blood can be thrown away and we can start over. (Ann Arbor, White, F) -Allow for opt-out, but its use should be the default. (Ann Arbor, White, F)
	d. Blanket consent for prospective spots (status quo)	-When a baby is born, run the tests, but ask permission for further use of the bloodspots. If the answer is no, then destroy the bloodspot card on that child. (Petoskey, White, F)

	e. Ask each time / contact me option	-For those that are stored without consent, researchers should have to contact or pay for the biobank to contact people for consent to do research. (Petoskey, Native American, F) -It's my blood, my body so don't disregard my voice! If it's for a project I agree with then go for it. If I have an ethical dilemma, I don't want my DNA used. (Ann Arbor, White, F) -I can choose to participate with research that I agree with and think is important. (Ann Arbor, White, M) -I would like to be notified for requesting use and to list the reasons they wish to use it. (Detroit, Hispanic, F) -I don't want to be bombarded with calls. (Petoskey, N/A, F)
	f. Tiered consent, or contextual consent requirements	-I would like to give a list of research that's fine and you don't have to contact me about types of research I want to give consent for. (Ann Arbor, White, F) -Blanket consent for some, individual consent from groups more prone to opt out. (Ann Arbor, African-American, M) -Blanket consent for certain tests and then mandatory consent for other tests. (Ann Arbor, White, F) -Public health and academic research allowed no matter what. Industry or other researchers would need to gain permission each time. Look for those who might have issues with bloodspot use, let them choose not to participate. (Ann Arbor, White, M)
	g. Incentivize decision-making or consent	-Pay me a dollar each time. (Ann Arbor, White, M) -Offer an incentive to anyone born after 1984 to contact the state in regard to consent for bloodspot use. (Petoskey, White, F) -Notification of information found with child research would be an incentive. (Detroit, Hispanic, F)
	h. Periodic consent	-I like the idea of having yes or no on the blood spot card itself. Yet, I would also like to see consent asked if it's used again after, say even 5 years. (Petoskey, White, F)
	i. Delivery methods	[Suggestions included telephone, Facebook, Twitter, online surveys (to gather public opinion on consent), Secretary of State, ballot, tax forms, education through physicians or pre-natal visits.)
	j. Timing	- More education about this issue for mothers/expecting mothers PRIOR to them giving birth!!! (Grand Rapids, Asian American, F) -You need to think about things before you just get a call and have to decide then. (Detroit, African American, F)
	k. Consent by proxy	-When does the child gain ownership of their own bloodspot? Is the child whose blood is stored notified? (Flint, Discussion) -[I am concerned about] fathers' rights. (Jackson, White, M)
	l. Challenges/ drawbacks of gathering consent	-If they can't even contact all the owners of bloodspots (pre 2010) already stored to gain consent, how can they be expected to reasonably gain consent for every experiment, every time? (Ann Arbor, White, F) -I deal with a lot of new parents who would not understand the benefits and or risks of this. (Jackson, White, F) -If a specific demographic of people say no, any research would be biased. (Jackson, White, F)
	m. No consent (mandatory participation)	-None of these concerns, in my opinion, have any merit. Religion / cultural superstition should not detract from public health. …Everybody should do this. It should be mandatory. (Ann Arbor, White, M) -Do not let people know what is going on. Government decides what to do based on the benefit of everyone. (Ann Arbor, Hispanic, M) -I would make a policy that allowed all bloodspots to be in the BioTrust. Use for all medical research without parental consent. (Jackson, White, F) -Consent is not needed for state-owned bloodspots; no consent forms. (Jackson, White, M)
	n. Informed dissent	-Maybe opt outs should be required to watch an informational video presentation at the Secretary of State so at least their opt outs

		are informed and no opting out from sheer gut reaction… Informed opt out. (Ann Arbor, White, F)
III. Privacy		-I wouldn't want a possible leak of mine or my child's information due to someone else's lack of responsibility. (Detroit, Hispanic, F) -If a researcher is irresponsible and our information gets out, what will happen? (Detroit, Discussion) -Respect others privacy, always ask before you use something that not belong to you. (Grand Rapids, Asian-American, F) -For how long is the personal information private if it is linked to the bloodspots? (Detroit, Discussion) -Is it possible for the spots to be anonymized? (Ann Arbor, Discussion)
IV. Economic issues		-Who is covering the cost of the Biobank and the BioTrust? (Grand Rapids, Asian-American, F) -Is there an annual report about finances and research that is being done? (Flint, Discussion) -Is this an appropriate use of tax dollars? (Ann Arbor, Discussion) -We have concerns about how the money made would be used. Would it go back to the people? (Grand Rapids, Discussion)
V. Governance		-How do they choose their board members? (Petoskey, Native American, F) -I would formulate a legislation permitting Michigan BioTrust for Health to the meaningful use of bloodspots. (Grand Rapids, Asian-American, M) - How do they choose which child's bloodspots are used for research? (Flint, N/A, F) -How are representatives chosen for the IRB? (Ann Arbor, Discussion) -I would figure out an ethical framework to ensure safe and fair research practices for bloodspots. (Ann Arbor, White, M) -Who are the researchers, and how are the researchers evaluated? (Grand Rapids, Discussion) -Who decides what researchers get to use the samples? (Jackson, Discussion)
VI. Research uses		-Researchers would benefit from the data and the ease of sampling. (Grand Rapids, Discussion) -I think that we should be checking for as many diseases…as possible for our next generation (Jackson, Hispanic, F) -I think having blood spot in the BioTrust is very useful in research work--which I think would be indispensably important for knowing lots of important things--Useful to mankind in future concerning their health. (Grand Rapids, Asian-American, M) -Among the no research areas, I believe there are too many factors that are not biologically related. These factors may provide important information about mental illness/learning disabilities/obesity… (Grand Rapids, Asian-American, F) -My only concern is to make sure that everyone has access to the research and the samples, as long as there aren't barriers. One way to oppress people is to pretend they don't exist. For example the census did not acknowledge same sex couples, which meant that there would not be funding for (this classification) of people. (Ann Arbor, Discussion) -I think that these could lead to selective breeding if it appears from the genes or evidence in blood spot a child would have undesirable traits, this could cause unnecessary fear. (Ann Arbor, White, F) -After initial testing, use them to develop/implement health programs in areas that show a need for certain diseases or noted lack of health in a community (Jackson, African-American, Male)
VII. Non-research uses		-Will this information be used for discrimination by employers/insurance companies? (Jackson, Discussion) -Can they use our children's DNA for law enforcement? What control do we have over if they use it? (Petoskey, Discussion) -[I'm concerned about] unethical research (cloning or other extreme examples). (Ann Arbor, Discussion) -[I'm concerned about] a new eugenics movement. (Flint, Discussion)
VIII.		-More of this sort of test should be done. (Grand Rapids, Asian-American, M)

Newborn Screening		-It's a good idea and we should do our best to do all the tests we can so we can have a new generation without diseases. (Dearborn, Arabic translation, Arab-American, F) -Screening for untreatable diseases…can I pay for that if I have money? (Ann Arbor, Discussion) -[I am] worried that a lack of informed consent can affect the community support for Newborn Screening. (Petoskey, Discussion)
IX. Return of Research Results		-I wonder why they didn't tell the person about the blood spot. And if they find a cure will they let the family know or would they sell it and make billions of billions of dollars while the family needs the cure? (Flint, African-American, F) -I wish BioTrust could make the result of the blood-spot test public in order to educate the mass population, the people could be made aware of the preventive measures of certain preventable disorders. (Grand Rapids, Asian-American, F) -Are researchers going to tell the status of the research to the mothers/families/communities? (Flint, Discussion) -I would like to be informed if a researcher found something wrong with my bloodspot or found something to help improve my health. (Detroit, African-American, M)
X. Trust		-There's nothing wrong with newborn screening. There's probably nothing wrong with the BioTrust—but there is a trust issue. If MDCH had been up front from the beginning, we would be more trusting. Need informed consent, need to ask people. (Petoskey, Discussion) -Can I truly trust you? African American people are always last to know. I want involvement and information. (Flint, African-American, F) -What other lab specimens are being taken without the knowledge of the person being tested? This well end as a trust issue…. (Petoskey, White, F) -Afraid of trust issue when public learns that bloodspots stored without their knowledge; if the government held this, what else are they holding? (Petoskey, Discussion)
XI. Race/ Cultural sensitivity		-Did the research start with the African-American race first? (Flint, African-American, F) -Are there any black people on this committee? (Flint, African-American, F) -Potential group harms are likely to accrue to minority populations. (Ann Arbor, Discussion) -Why ask us now? You usually don't ask black people about any new discoveries when we find out usually everything is over and we are dead. (Flint, African-American, F) -There may be cultural reasons that people don't want (DBS) to be used. (Ann Arbor, Discussion)
XII. Emotional sensitivity		-…We are talking about my own kid's blood! (Dearborn, Arab-American, F) -Although I myself am not angry, many people will be angry they weren't asked first. (Petoskey, Native American, F) -I am put here on this earth as their caregiver… And besides God I don't believe anyone could love my child more than me. (Detroit, African-American, F)
XIII. Support for the BioTrust		-I think [the] BioTrust is really useful and helpful. I hope in the future more people will be aware of the BioTrust and gain a deep knowledge about it. (Grand Rapids, Asian-American, F) -The benefits seem to outweigh the concerns. (Petoskey, White, F) -This is fantastic. Any opportunity for more/improved research that leads to embetterment of large groups of people is awesome. (Ann Arbor, White, M)