Clinical Epigenetics

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Black community member perceptions and ethics recommendations on epigenomic research

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Abstract

Background Social epigenomics research investigates links between social experiences and epigenetic modifications, which may ultimately impact health. Such research holds promise for precision medicine and addressing health disparities based on social conditions, but also brings unique ethical challenges. The linking of social experiences to biological changes risks pathologizing experiences, potentially leading individuals and communities to be seen as 'damaged.' This stigmatization or stereotyping based on experiences also risks placing disproportionate personal responsibility for health. These risks are likely to be amplified in historically marginalized communities already facing discrimination. It is therefore essential to engage members of historically marginalized communities to explore attitudes about social epigenomics research. This study focuses on the Black and African American (B/AA) population in the USA, studying perceptions of social epigenomic research participants, research decliners, and broadly representative community members to identify perceived benefits and risks of social epigenomic research as well as strategies to maximize benefits and lower risks for both participants and communities.

Results Both research participants and community members perceived potential benefit of social epigenomic research for the B/AA population. While most research participants did not perceive research related risks, community members identified risks both specific to social epigenomic research and more generalized to medical research. Several of the risks identified, and a belief that the likelihood of harms was greater than the likelihood of benefits, were based on past research injustices to B/AA research participants and mistrust in the medical and research enterprise. However, community members provided concrete strategies for maximizing the chance of benefits and lowering risk of harms including acknowledging and addressing biases and past injustices, ensuring transparency and understanding, positive framing of research, thorough research and dissemination, and engaging with communities before, throughout, and beyond the research process.

Conclusions While B/AA community members identified risk of both individual and community harm from social epigenomic research, they also perceived potential health benefits for the B/AA community. Through concerted efforts to apply community recommendations to lower risks and enhance benefits, researchers can conduct ethical and valid epigenomic research that aims to address health disparities with historically marginalized communities.

Keywords Community, Black or African American, Epigenetics, Social experiences, Ethics

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Background

Social epigenomic research links experiences to epigenetic modifications (e.g., DNA methylation) to understand how social factors can cause biological changes influencing health or disease risk. Such research holds promise as a step toward development of precision medicine interventions that address health disparities based on social conditions, yet it also presents unique risks and ethical challenges. Ethicists and social scientists have long recognized issues that may arise in socially sensitive research in study design, implementation, interpretation, and application of findings that may require different considerations [1]. In social epigenomic research, this sensitive information is combined with the collection of genomic and epigenomic data, often subject to data sharing policies, which have seen debate about de-identifiability, privacy risks, and varying public attitudes about privacy and data sharing [2–4]. The linking of these data types then demands new considerations for the conduct and dissemination of research.

First, the linking of data on social experiences to biological (epigenomic) changes may pathologize experiences and create a biosocial model of health and illness that can lead to stigmatization and stereotyping [5–7]. These risks may not only impact research participants, but also populations that may face stereotyping based on findings from a sample of their population. Additionally, this may be used to place disproportionate personal responsibility for health on individuals and communities rather than placing focus on supporting societal change to address social determinants of health [5]. Social scientists and ethicists have acknowledged that while these studies address important scientific questions that may improve social policies and health care, social epigenomics requires a multi-disciplinary approach to facilitate development of safeguards that transcend traditional views separating the biological and the social drivers of health [5, 6, 8]. It is also essential to recognize that a key stakeholder in these conversations must be the individuals and communities that will take part in and be impacted by social epigenomic research.

These ethical challenges and the need for community involvement and new considerations of policy may be particularly salient for historically marginalized racial or ethnic minorities in which structural racism has contributed to intergenerational harm and social determinants of health [7, 8]. This includes Black and African American (B/AA) populations in the USA, who while not defined as a vulnerable population by the common rule [9], may be considered a vulnerable population by the definitions of multiple policies and based on previous unfair and inequitable treatment in research and a greater likelihood or degree of wrongs [10, 11]. Indeed, there is a troubling history of research injustices against B/AA research participants that has spanned over 400 years with noted examples into the 1990s [12]. Additionally, potential risks to communities to which research participants belong have been acknowledged, with the greatest risk to communities that already face stigmatization and/or discrimination [13, 14]. For example, demonstrated harms to the Havasupai tribe occurred through unconsented uses of research samples from a subset of the community [15]. Yet, even when research is conducted to ethical standards research may be misappropriated to support racism, such as the contortion of genetic research on educational attainment used by a mass shooter targeting Black individuals in 2022 that yielded calls for greater consideration of moral responsibilities for potential group harm by those who conduct research [16, 17]. With the inclusion of socially sensitive or potentially stigmatizing experiences in social epigenomic research, addressing this by efforts to incorporate the sociocultural and political realities of vulnerable populations is necessary and requires partnership and participation from community members to ensure protection and balance power [18].

Our study team identified both an opportunity and responsibility to use a community-based approach to interrogate attitudes about social epigenomic research in B/AA community members due to a social epigenomics study at our institution investigating how social experiences may impact epigenomic signatures in immune cells and be associated with increased risk for asthma exacerbations in children. The study enrolls B/AA children, for whom previous studies have shown greater risk of asthma and significantly higher disease-related morbidity than non-Hispanic, White children with more research needed to understand the underlying factors contributing to this disparity [19–21]. Accordingly, the ongoing study at our institution seeks to use epigenomics to understand potential factors and underlying mechanisms for these health disparities in childhood asthma, which could inform future interventions and therapies. To do so, we acknowledged the need to assess cohort representativeness and implemented several metrics to provide a comprehensive spatial assessment of our study cohort with respect to a broader target population [22].

In this paper, we leverage the context of this ongoing asthma study to investigate attitudes about social epigenomic research in the B/AA community. This was approached through two objectives. The first was to explore perceptions of individuals from a historically marginalized B/AA community who were approached to participate in a social epigenomic research study. This was investigated through in-depth interviews exploring perceptions of benefits and risks with parents who enrolled with their child in the asthma epigenomics study

at our institution and asking decliners of the asthma study their reason for choosing not to participate. The second objective was to identify attitudes and strategies to minimize and mitigate unintended community harms of social epigenomic research from members of a historically marginalized community, who may be impacted by community harms from research even if they are not active participants. This was accomplished through focus groups about social epigenomic research with B/AA community members who had not been approached for or enrolled in the asthma epigenomic study at our institution.

Methods

Study context

This study took place in the context of the Stress, Epigenomics, and Asthma (SEA) study, investigating potential links between social experiences, epigenomic signatures in nasal mucosal samples, and asthma exacerbations. B/AA children and their parents/guardians were eligible for SEA study participation if the child presented to the emergency department (ED) or was admitted to Children's Mercy Kansas City (CMKC), a pediatric academic medical center located in the central USA, with symptoms of respiratory distress. Families were approached at the time of their child's ED visit or during inpatient admission for recruitment and informed consent. The SEA study enrolled participants from March of 2021 to May of 2023. At the time of SEA study enrollment, parents/guardians completed surveys on perceived racism, resilience, social support, demographics, their child's medical background, and adverse childhood experiences for themselves and their child. They also gave permission for collection of a nasal swab for epigenome analysis, cheek swab for genotyping, and an optional blood draw for functional studies from their child. Children assented as appropriate based on age and development, and children aged 7 years and older completed a subset of the above survey measures dependent upon their age.

Objective 1: perceptions and enrollment of individuals approached for social epigenomic research

SEA study participant interviews

Parents/guardians who had enrolled with their child in the SEA study were subsequently recruited for in-depth interviews about their experiences and views related to the SEA study. Recruitment and consent for interviews occurred after all SEA study data and sample collection was complete. SEA study participants were approached for interviews based on coordinator availability, time during the clinical encounter, and progression of this interview study. During the time period of interview recruitment, 65 participants enrolled in the SEA study. Of these, 16 families were approached for the interview study and 16 mothers consented to and completed an interview. Interview participants were recruited from December 2022 through April 2023, when saturation was reached. Thematic saturation, where no significantly new ideas were emerging in interviews, was identified though periodic discussion of investigators CB and TB, who conducted interviews and reviewed interview transcripts, respectively. The interviews explored parents' understanding of the SEA study, experience completing SEA study activities, benefits and risks of SEA study participation and research, and benefits and risks of social epigenomics research in general. Interviews were conducted by phone after the SEA study encounter and participants were compensated for their time.

Interviews were audio-recorded and transcribed. Two investigators (CB and TB) deductively coded interviews based on the interview guide and topics related to SEA study processes and then used a content analysis approach to identify themes within each topic.

SEA study decliner reasons

From initiation of the study reported here in September 2022 to May 2023 when SEA study enrollment ceased, prospective data were collected on reasons for declining the SEA study. After a parent/guardian declined participation in the SEA study they were asked whether they were willing to share their reason(s) for declining. If they consented to share their reason(s), it was recorded and categorized based on previously reported categories for declining genetic research [23]. Study personnel also recorded who was involved in the decision to decline the SEA study. No demographic data were included with this prospective data collection on SEA study decliners. However, a retrospective analysis of socio-demographic features, healthcare factors, and logistics of recruitment is provided as ancillary information in file Supplemental SEA Study Participant and Decliner Comparison.

Objective 2: community perceptions and strategies to lower risk of group harms

Community focus groups

Individuals from the Kansas City region who were 18 years and older and identified as B/AA were eligible for participation in community focus groups that discussed social epigenomics research, using the SEA study as an example. To facilitate diverse demographic representation, recruitment flyers were shared broadly including at local libraries, businesses, churches, and community service organizations with a QR code to express interest via a REDCap [24] form. Demographics were collected to build diverse focus groups and guide future recruitment toward representation across ages, education

levels, gender, and status as caregiver of a child (due to the pediatric focus of the asthma study and our institution). All who expressed interest were invited to join a focus group. Focus groups were available to attend in-person at community locations throughout Kansas City, MO or virtually using an online conference call platform. Before focus groups began, two community advisors who identify as B/AA were invited from the Children's Mercy Research Institute Community Advisory Board to join the study team (SDY and DL) and received training in human subjects research and focus group facilitation. To facilitate comfort and openness for participants, focus groups were moderated by these community team members. CMKC staff consented all participants prior to the focus groups and were present to audio-record the session, take notes in a manner visible to the participants, and to issue gift cards for participant compensation.

The interview guide, informed by community study team members, began by exploring perceptions of genetic research in general. Participants were then educated by a genetic counselor (CB) about epigenetics followed by a description of social epigenomics research, which was presented as research that "links our social experiences to changes to how our genes work in our bodies that impact our health" with the SEA study presented as an example (see Supplemental Fig. 1). The moderator then explored perceptions of social epigenomic research including potential benefits and risks for participants, society, and minority communities. Two lay headlines, one referencing how trauma can leave biological traces [25] and one referencing the linking of genes to social phenomena [26], were presented for discussion by the group. Participants were asked to share their views on such research and how it was reported in the headlines and then were asked to discuss ways that researchers can lessen the risks of research that links social experiences to genetics and health.

Focus groups were audio-recorded and transcribed. Community moderators and CMKC study staff met periodically throughout the conduct of focus groups to discuss common and emerging themes. As thematic saturation was approached, it was noted young adults had been underrepresented in previous groups. Therefore, a focus group prioritizing recruitment of participants in their teens and 20s was held which allowed better inclusion of young adult perspectives and for the team to agree that thematic saturation had been reached after 7 focus groups with 54 participants. CB and TB worked collaboratively to inductively code the first three transcripts using a grounded theory framework and develop a draft codebook. Additional transcripts were coded by either CB or TB, with periodic review and collaborative discussion to ensure agreement and adjustments made to the codebook as needed. The codebook and interpretation based on grounded theory analysis were presented to the community study team members for discussion and edits until agreement was reached on data interpretation.

Results

Objective 1: perceptions and enrollment of individuals approached for social epigenomic research

SEA study participant interviews

According to SEA study inclusion criteria, all were mothers to children who identified as B/AA. Their SEA study participating child ranged in age from 0 to 12 years ($\mu = 4.97$).

When asked about potential benefits of the SEA study, participants expressed a desire to contribute to research that could help their child or others with asthma and hoped the study will improve prevention, diagnosis, and treatment for asthma.

> *"They will find out more things that trigger it…more things to look out for."—Interview Participant 3*
> *"I think that they could find a cure or a medicine or something for the kid, for the small kids that they're doing these studies for."—Interview Participant 13*

Several participants also expressed appreciation that a study was focusing on B/AA children.

> *"I've noticed there's a lot of studies done on other ethnicities other than Black people. I was just kind of shocked, like, 'Wow, they're actually trying to figure stuff out now.'"—Interview Participant 6*

Participants also appreciated that the SEA study asked about common social experiences they felt are rarely addressed in health care, such as racism and adverse childhood experiences. A small number felt it was difficult or traumatic to revisit these past experiences, but most said they felt comfortable completing the SEA study survey and sharing their experiences. Participants hoped the study might build empathy or awareness of shared experiences.

> *"Because I've never been asked those type of questions before and that stuff comes up a lot—sometimes, those questions. And it just made me feel like somebody cared."—Interview Participant 1*
> *"A lot of us as parents will be able to understand that it's not necessarily anything that we did to the kids, but there are things that they've gone through in their lives that have helped trigger this."—Interview Participant 5*

Most did not identify personal risks of participating nor societal or group risks. Participants seemed to focus on physical or medical risks, which they did not see as

present, and to trust that the research could have benefits for children with asthma.

> *"No, I honestly can't see any risk or any bad that would be being involved in this type of study. Because it's all educational …you're actually trying to figure out something."—Interview Participant 11*

A small number of participants noted potential misuses of genetic information or had concern that experiences of racism or trauma collected in the asthma study surveys could be used against the community through negative stereotyping. While not necessarily by name or with specific or accurate details, these participants referred to the story of Henrietta Lacks [27] and the Untreated Syphilis Study at Tuskegee [28] as examples of past research injustices against the B/AA community and as context for their fears. These participants in the asthma study expressed trust and hope that this would not occur in the SEA study and discussed transparency and ensuring privacy as ways to protect participants.

> *"I just have concerns in general that it will be used for something other than what I signed for it to be used for. I mean, I'll just look up 20 years later, and then there'll be a clone of [child's name] "—Interview Participant 15*
>
> *"My black people paranoia says, "You guys have my DNA. What are you guys going to do with it?" You know what I mean? [laughter] That's my culture being afraid of white people though, you know what I mean? Because you all got a history of injecting us with syphilis and things of that nature…We gatekeep and we don't trust, because you know what happens when we don't gatekeep."—Interview Participant 16*

SEA study decliner reasons

During the period of prospective data collection about SEA study decliners, 20 families declined enrollment in the SEA study. Of these, 8 consented to share their reason and 6 of the 8 indicated they did not want to participate in research in general. One other decliner indicated that they felt the child's other parent, not present at the time, would not approve of the study and another cited a previous traumatic experience from losing a child to a respiratory illness. For these 8, the decision to decline was made by a male parent or guardian in half ($n=4$) and a female parent or guardian in the other half ($n=4$). A retrospective comparison of characteristics of participants and decliners (see file Supplemental SEA Study Participant and Decliner Comparison) did not show statistically significant differences in socio-demographics or healthcare factors between the two groups.

Objective 2: community perceptions and strategies to lower risk of group harms

Community focus group participants

Demographics of the 54 participants in 7 focus groups (5 in person and 2 virtual) are presented in Table 1. To match the inclusion criteria of SEAS participants, all focus group participants identified as B/AA. A majority were female (80%) and 57% were currently or in the past a primary caregiver for a child. Participants ranged in age from 18 to 79 years and showed broad variability in the highest education level completed, with 54% having completed high school or less and 32% having an undergraduate or graduate degree.

Benefits and harms of social epigenomic research

Focus group participants identified potential benefits to genetic and social epigenomic research, including specific discussion of opportunities to improve health for B/AA communities and community members. These

Table 1 Focus group participant self-reported demographics

Demographic category	Participants *n* (%)
Gender	
Female	44 (81%)
Male	10 (19%)
Age	
18–29	15 (28%)
30–39	11 (20%)
40–49	6 (11%)
50–59	10 (19%)
60 +	10 (19%)
No response	2 (4%)
Race[a]	
Black/African American	54 (100%)
American Indian/Alaskan Native	2 (4%)
Other	0 (0%)
Ethnicity	
Hispanic or Latino	0 (0%)
Not Hispanic or Latino	53 (98%)
No response	1 (2%)
Primary caregiver for child (past or current)	
Yes	31 (57%)
No	23 (43%)
Highest education level completed	
Less than high school	2 (4%)
High school	27 (50%)
Associate's degree	6 (11%)
Undergraduate degree	7 (13%)
Graduate degree	10 (19%)
No response	2 (4%)

[a] Participants could select more than one racial category

benefits fit into themes of *Understanding disease risks and therapies, Building awareness,* and *Sharing knowledge and awareness in the community*. Table 2 presents each theme with a description and example quotes from the focus groups relating to social epigenomic research. While each theme could relate to medical research in general, Table 2 reflects quotes representing ways that participants discussed specific benefits of social epigenomic research such as awareness of how stresses in the home and environment could impact the immune system and health, often relating this to personal experiences with asthma. In the *Building Awareness* theme, participants discussed a benefit of awareness of what may be trauma, noting that when stressors are chronic individuals may not recognize them as traumatic but as "normal".

Participants also identified areas of potential harm, including themes of *Generalizations and assumptions*, *Limitations of study findings*, *Benefits to other communities*, and *Lack of transparency*. Descriptions and example quotes for each theme are in Table 2. While some of the harms discussed may apply across communities, many were felt to be more salient or to present greater risks to B/AA communities. For example, in *Generalizations and assumptions* participants discussed how researchers may label a community based on findings in a sample and that any labeling of B/AA communities was expected to be negative based on their experiences of discrimination. Furthermore, generalizations may not account for the history of discrimination and oppression that can lead to difficult shared experiences. Also, within the theme of *Benefits to other communities* participants discussed how even if research was conducted within B/AA populations any health interventions developed from the work may be less accessible to B/AA individuals due to high costs of healthcare and racial economic disparities in the USA.

Many harms were shared in both discussions about genetic research in general and targeted conversations about social epigenomics research. However, discussions on social epigenomics research brought additional specific thoughts. In particular, within the theme of *Limitations of study findings* participants discussed potential challenges in defining and recognizing trauma noting the uniqueness of each person's experiences and how they view them can bring challenges in collecting standardized data on social experiences. They also noted that with the broad range of physical environment and social experiences that could impact health, researchers may not select the most relevant variables and miss important factors. Also related to the uniqueness of experiences and reflected both in themes of *Generalizations and assumptions* and *Limitations of study findings*, participants discussed potential for over-generalizations without recognizing the different ways that individuals may respond to experiences that can make conclusions or groupings difficult. Of note, participants rarely objected simply to the idea of linking social experiences with epigenetic changes and health but focused on potential harms from ways in which such research could be done poorly or misused within the presented themes of potential harms.

Participants overwhelmingly felt that B/AA community members were less likely to receive the benefits or would receive them later, while B/AA community members and communities would be more likely to experience harms from the research. They stated their views were based on previous personal and community experiences with injustices and mistrust in medical and research enterprises. While some referenced well-known research injustices such as Henrietta Lacks [27] and the Untreated Syphilis Study at Tuskegee [28], more often participants discussed more personal experiences such as not benefitting from local community improvements or medical experiences such as misdiagnosis, not being listened to, or treated as drug seeking when in pain. These experiences strongly informed attitudes about the likelihood of benefits and harm.

> *"I give the good effects a good 40 and then bad effects a good 60, just because as we are the African American community. We are frowned upon whether we're doing good or bad. You know what I'm saying? So regardless if we get these genetic mutations or whatever and it helps us, we're still going to be frowned upon. There's going to be some down effects of it, but I do think it could help."—Focus Group 7*
>
> *"We look at things when they happen, and improvements come to other communities, and they come to our community last. So those outcomes may go to suburban communities, wealthier communities, and then funnel down to our communities. It's like being invited for dinner, but when you get there, everybody else is already eating, and there's not much left for you to eat…There would have to be a concerted effort to be able to ensure that minority and low-income communities would benefit just as much as other non-minority and non-income-based communities."—Focus Group 2*

Strategies to maximize benefits and minimize harms

While some participants reported skepticism that risks for B/AA communities could be lowered, many participants shared ways that researchers could improve the chance of benefit and lower the risk of harms to B/AA community members and communities. Themes arising from this discussion include *Recognizing and addressing biases and past injustices, Transparency and ensuring understanding, Positive framing of research,*

Table 2 Themes with description and example quotes illustrating potential benefits and harms of social epigenomic research

	Theme description	Example quotes[a]
Potential benefits		
Understanding disease risks and therapies	Contributions to understanding risks and causal factors for disease as well as the development of new therapies.	*"So there are a lot of different environmental things that we need to know about because if we know about them younger, maybe we can do things that can put us into a position to where we have a longer life. But…, knowing is half the battle, and right now, we don't know the half of that battle because we don't have a full picture of that."*—FG2
Building awareness	Building personal knowledge of that social factors can impact health and awareness of how your experiences may be interpreted as "trauma".	*"I think it's a good thing because I don't think a lot of people, especially younger parents, realize that there are certain triggers that affect your immune system that also affect different childhood diseases and things"*—FG4 *"It also brings about a self-awareness aspect too, so what your experiences are, what your trauma is. Sometimes you think your trauma is just normal. Whatever you're going through is normal, but when you think about it, it's really not. So how do you want that to impact whatever family or community that you contribute to? So I think that's really important."*—FG7
Sharing knowledge in the community	Sharing knowledge among family and community members to spread information that supports health.	*"So what we learn about our experiences and how it affects our genes and our health and things like that, we can pass it on. And every time we pass it on, that's more people that are aware."*—FG3
Potential harms		
Generalizations and assumptions	Labeling of individuals or communities based on research findings that ultimately leads to treating others differently.	*"What worries me is when the young person, whether they're little or big, when they're growing up and their parents emphasizes things like something's wrong with them. But their parents get this from a doctor or something, and sometimes I think they can push that too far"*—FG5 *"It could be used to be like, "This group of people are better because of this gene," or, "This group of people are bad because they have these genes." And that way, create a lot of division and stuff"*—FG3
Limitations of study findings	Harm from poorly done research that does not adequately consider all relevant factors (e.g. social and physical environment) or does not recognize the limitations of data collection and analyses in the reporting of the findings.	*"And because what they're doing is for children, parents who fill out some of the information that they request, they're not always honest. They don't really tell you everything that's going on in their home, why that child might be stressed, that their living environment is not compatible with a person with asthma…But if you don't have all the information, then your results can't be accurate."*—FG1 *"I feel like everybody's experiences are different. So it might be hard to come to a conclusion into what it specifically is, so that leaves a lot of room to be—confusion and can be interpreted different ways… they're going to be like, 'It's definitely that if you're like this, you're going to have this.' So it's like, 'But is it like that for everybody? How is it? Can it work for all people if you use this conclusion? Does it fit everybody?'"*—FG3

Table 2 (continued)

	Theme description	Example quotes[a]
Benefits to other communities	Research benefits that help wealthy and White communities first and may only come to Black communities later, if at all. This may be due to a lack of focus on conditions that impact Black communities, using Black individuals as "guinea pigs" to help others, or high healthcare costs that make the latest advancements inaccessible to individuals with lower incomes.	*"So can I just say I would think a benefit would be finding cures. But at the same time, are they going to find cures for diseases or different types of conditions that black people have? Because a lot of research is done on things that—or there's a lot of money for cystic fibrosis, but what about sickle cell? So what about us?"*—FG4 *"Well, we've always been the guinea pigs for a lot of things."*—FG2 *"I feel like they use us to say that they want to help our kind and da, da, da, da. But then they take their research, and they put thousands of dollars and say, "You got to pay this amount of money." And we know who's at the bottom of the charts right now when it comes to pulling out the dollars. So it's like at the end of the day, I feel like they're not really doing it for us. I feel like they want to say they using it to help our community, but I feel like they're using it and they taking it to make money and at that just control kind of control our population."*—FG7
Lack of transparency	Lack of full consent and transparency for all study activities, ways that data will be used, potential findings, and risks to individuals and communities.	*"I can understand finding out genetically things like that, but is that really all you planning on doing with this? So that's the hesitation of it because are you truly going to do what you think you're going to do? Because how many times have you said one thing and did another?"*—FG6 *"So it's informed consent, number one, but number two, since then, the African American community has a distrust of health and healthcare providers because you never know, as somebody said earlier, is it being done for population control? What is the outcome, and how is it going to help the community versus any negative outcomes or other nefarious means that can actually hurt the community? "*—FG2

[a] FG = focus group, identifies in which of the seven focus groups the statement was made

Thorough research and dissemination, and Engaging with communities. Each theme is shown in Table 3 with a description and example quotes. The strategies address actions that can be taken by researchers at all stages of research, including before a research study begins and after a study ends. Many of the recommended strategies directly address the risks of harms that were discussed in focus groups, though any one recommendation may apply across multiple potential harms. For example, ideas within the themes of *Thorough research and dissemination* (see Table 3) can help address themes of potential harms including *Generalizations and assumptions* and *Limitations of study findings* (see Table 2) by improving research conduct and dissemination. Likewise, *Engaging with communities* can address concerns across all themes of potential harms by getting direct community input across research conduct, dissemination, and translation.

Focus group participants also noted that because existing mistrust was built on a cumulation of past experiences that were shared in the community, continued failures by even a small number of researchers to meet expectations would further erode trust. Furthermore, participants noted that only observed actions by researchers could re-build trust, not merely words or promises.

> *"You have to show me that you are really about what you say you're about. You got to show me. You can't tell me. You got to show me, so."—Focus Group 2*

Discussion

Existing reviews and commentaries have discussed ethical aspects of epigenomic research for informed consent [29], data sharing [3, 4], and return of results [30], including consideration of vulnerable populations [8, 31, 32]. However, our study is, to our knowledge, the first empirical study of attitudes about social epigenomic research in a vulnerable population and the first, empirical or otherwise, to focus on the B/AA population. This study utilized multiple methods and groups to provide a multidimensional perspective on the ethical aspects of social epigenomic research involving this population, including participants who had direct interaction with social epigenomic research, decliners who were approached but opted not to participate, and the broader community that may be impacted by group harms of research. While this study focused on the B/AA population, the results are relevant to other vulnerable communities. Many of the findings support previous conceptual analyses about potential harms of epigenetic research for vulnerable populations (including indigenous, autistic, transgender, and refugee or asylum seeking populations) such as stigma and discrimination based on findings, inability to afford treatments developed based on research findings, and viewing individuals or communities as responsible for epigenetic harm and resulting health concerns rather than using findings to support environmental or social justice initiatives that support health [8, 31, 32]. Community members in this study also supported protections for vulnerable communities voiced in conceptual analyses such as engaging communities in study design, transparency in informed consent, and careful dissemination of results [8, 31, 32]. However, our empirical approach identified novel perceptions of risks (benefits to other communities) and protective actions (recognizing and addressing biases in studies and study teams, positive framing of research) based on experiences of the impacted population. These results provide community-informed guidance on ways to maximize benefit and minimize harm of social epigenomic research not only in the B/AA population, but also in other vulnerable communities that face societal discrimination.

The potential benefits of social epigenomic research, shared here in both interviews and focus groups, to improve care for themselves, family members, and others, have been reported both in other genetics research [33–35] and in B/AA populations in research [36, 37]. However, both SEAS participants and broader community members expanded this idea to specific benefits to the B/AA community, which was seen as a key benefit to research and important factor both for motivating participation and building trust between the research enterprise and the community. Additionally, while the collection of information about sensitive and stigmatized experiences brings risks and ethical considerations [1, 38], SEA study participants expressed positive attitudes toward inclusion of social factors that they felt are often ignored in health care.

In contrast, there were some distinctions in perceptions of risk between the SEA study participants interviewed and the focus group participants. Most SEA study parent participants interviewed did not identify risks of the SEA study. The small number who did, voiced concerns based on past misuses of samples and data from B/AA individuals but had hope and trust in the research team not to repeat those injustices. Participants in the SEA study may have a positive bias as they had recently enrolled in a social epigenomic research and hoped for benefits from the research. In comparison, all focus groups identified several potential harms of social epigenomic research, many of which also reflected the history of research injustices involving B/AA individuals and communities in the USA. Focus group participants also tied their perception of increased likelihood of harms for B/AA individuals and communities from social epigenomic research to past research injustices and personal

Table 3 Focus group participant ideas of ways to lower risks of social epigenomic research, particularly for B/AA communities

Theme	Theme description	Example quotes[a]
Acknowledge and address biases and past injustices	The need for researchers to recognize and address both biases that exist in themselves and team members and past injustices toward B/AA communities. This can be addressed by acknowledging injustices with participants, including study team members with shared health or cultural experiences to participants, and considering biases in self and study team members that may impact findings.	*"Do the researchers have the same issues? Say, the people that are doing the research, do any of them have the history of asthma that they can relate… [new speaker]Yeah. You're not seeing me as a specimen. You're seeing something you can relate to. Yeah."*—FG1 *"I do have one other thing. As you do this, do not put together a group, test group, whatever you want to call it, and you come to a minority community—and I'm just going to be blunt—you come with a white face. If you're going to talk to the minority community, have somebody there that looks like them, that they're not afraid to talk to and ask a question"*—FG2 *"If it's something that's negative—but if I did research and got a negative result, I would kind of back up kind of like some of you have said and kind of try to see why did I get that. Was it that I didn't consider the environment, things like that? What led to that? And is it real, or is it—do I have a preconception?"*—FG4
Ensuring transparency and understanding	Transparency by researchers in all the ways that data may be used and how data collection and study findings may impact participants and communities. This requires clearly written materials, willingness to have multiple discussions to ensure understanding, giving time for decision making, and continued interaction throughout a research study.	*"Also, they might be scared if what they shared was too much or what would happen [to] information that they give. So sort of know what's okay, what's going to happen if you give out certain information. And maybe you're not supposed to give out certain other information. So yeah. Especially people in a community with trauma or anything. They grew up in a ghetto. They don't know how much is okay to share, how much is not okay to share, so."*—FG3 *"If you're going to explain it to people about the research and, again, how it's going to be used or how you would envision it being used, letting people know that upfront. But also, again, let them know, take some time, and then come back to them… Research in the minority community is not going to be at the same pace that it may be in a non-minority community. It may be a little bit slower. It may be a little bit harder. But if you work to build the relationships, the data that you get will be so on target and will help in so many different ways."*—FG2
Positive framing of research	Not just focusing on vulnerabilities but studying positive outcomes and framing research findings in a way that highlights actions that can be taken to positively impact health.	*"When I think about just about all of our parents had so much trauma in their lives. But we got a lot of kids that are doctors, lawyers. I mean, we have a lot of kids that rose above all of the areas that they lived in and what they were around. They need to be looking at what are the success stories, what can we learn from the success stories. How did they rise above their circumstances? And what did that do? Which gene did they turn on or off in order to do that?"*—FG3 *"So rather than labeling, it's kind of let me better understand so we can develop or have resources to support… [new speaker] This is just limiting versus limitless if you're giving me the options so I know how to improve myself."*—FG7

Table 3 (continued)

Theme	Theme description	Example quotes[a]
Thorough research and dissemination	Incorporating activities that support optimal data collection and analysis so that findings are valid and reliable. Dissemination that is responsible in reporting both findings and limitations, and that includes efforts to share findings with the communities that are impacted by the research.	*"If you're comfortable, you're more willing to give more information, especially if it's experiences. It's hard to capture people's experiences, I don't know, on paper or whatever. But if you're uncomfortable, you don't know what—if they're uncomfortable, they're holding back. So you're not getting the full thing that you need for your research, depending on how much they're giving or not giving to get their full story. Also, how you capture their experiences and what kind of questions you ask them. Some specific questions might have been given an answer to certain questions, but we'll leave out certain things because we didn't understand it and interpret it differently."*—FG3 *"Share the data. What is the purpose of doing research if you're not going to share the data, whether it be good or bad, with the community that you're using as your test models?"*—FG4
Engaging with communities	Engaging communities in ways that not only includes community members in all stages of the research process, but that also builds relationships and supports participants and communities before and after research studies.	*"But I think it would be advantageous for people who are doing research to also give the parents and the people in the studies resources and information that helps them and not just use them as a test participant."*—FG4 *"How about we find better ways to make everything better. Let's get some fresh fruits or vegetables out there. And maybe even some people who need medications who can't afford it. Let's get them help. Let's get things on the road."*—FG5

[a] FG = focus group, identifies in which of the seven focus groups the statement was made

experiences with health care. The discussion of group harms for the B/AA community was also unique to the focus group setting and may have been elicited by the group discussion setting focused on the B/AA community and/or the presence of community moderators. The lack of risks noted in SEA study participants compared to community members reinforces the need for careful discussion of risks during consent and may support arguments for the inclusion of community or group risks in consent forms, which is currently not required of IRBs [39]. It is also worth noting that some harms discussed by community members match published ethics concerns of epigenetic researchers such as concerns about privacy and perceptions of determinism based on exaggerated or misleading claims made by researchers or the media [40]. Yet our study revealed additional concerns from community members such as benefits going to other communities and lack of transparency. In another slight contrast, while community focus group participants shared broad concerns about generalizations and use of findings against communities, Dupras et al.'s [40] survey of epigenetic researchers reported concern for more specific uses such as in life insurance, direct-to-consumer testing, immigration, or forensics that could harm individuals or communities.

Importantly, our focus groups identified harms more specific to social epigenomic research such as inaccurate findings due to difficulty defining and recognizing trauma and failure to consider the broad range of physical environment and social experiences that could impact health outcomes. Focus group participants also noted the potential for over-generalizations without recognizing the uniqueness of individual experiences and responses to experiences. These perceived harms echo concerns about methodological abilities to capture the complex milieu of environmental and social contributors to disease [41] as well as impacts across timing, duration, and type of social factors [42] discussed in commentary by social epigenomic researchers and a scoping review of social epigenomic research, respectively. For community focus group participants, these social epigenomic focused potential harms, along with the more general research harms of benefits going to other communities and lack of transparency in research often stemmed from or built upon mistrust in research and the medical enterprise. The theme of mistrust in research also follows through the data on reasons for declining participation in the SEA study. Though the number of individuals who shared their reasons for declining was very small, the finding that 75% indicated they did not want to participate in research in general is consistent with mistrust in the research enterprise in B/AA populations and differs with reasons for decline of genetic research in other populations [23]. The discussions of mistrust, with attribution both to a history of well-known research injustices and to personal experiences within the healthcare system, that run through each source of data for the study demonstrate the ramifications of the deep-seated mistrust of medical research in the B/AA community and the cumulative consequences of continued wrongs.

While it's important to recognize the mistrust of the medical research enterprise in B/AA populations reported here and elsewhere, it should also be seen in the context of perceptions of potential benefit and altruism which motivate participation [37, 43] Together these findings suggest that many B/AA individuals simultaneously see benefit and may be willing to participate in research that may help their community, while holding a view of increased vulnerability to research harms that may require extra considerations. Indeed, interviewed SEA study participants had already done so. Researchers have a responsibility to take concerted steps to address mistrust and concerns that are key factors across the research enterprise and may be amplified for social epigenomic research. Focus group participants frequently expressed appreciation to be consulted on the topic, as well as the value they placed in having B/AA study team members conducting consent and moderating focus groups for this study.

The findings of our study support recommendations that have been made both in the context of epigenetics and social and behavioral genomics studies in vulnerable populations such as strategies for careful dissemination and community-driven partnerships [8, 16, 17, 44, 45], but focus group participants recommended additional actions. Many of the recommendations interconnect and all can be supported by involving members of vulnerable communities in all stages of the research process. Figure 1 demonstrates the interconnectedness of these recommendations and the centrality of community engagement to meeting the recommendations and building trusting relationships with communities. Indeed, engaging communities in research is already recognized as important to improve research relevance and quality [46]. However, in a social epigenomics context, this may hold particular importance as community members are essential informants on the social factors that impact their community members. When integrated into research teams they can help to design understandable study materials, develop accurate and relevant data collection, address biases and educate other study team members, and identify positive actions and outcomes that can be supported by research. Conversely, as study teams work to improve study conduct and communication, address biases, and support positive actions from research, relationships with communities can be bolstered. Therefore, building

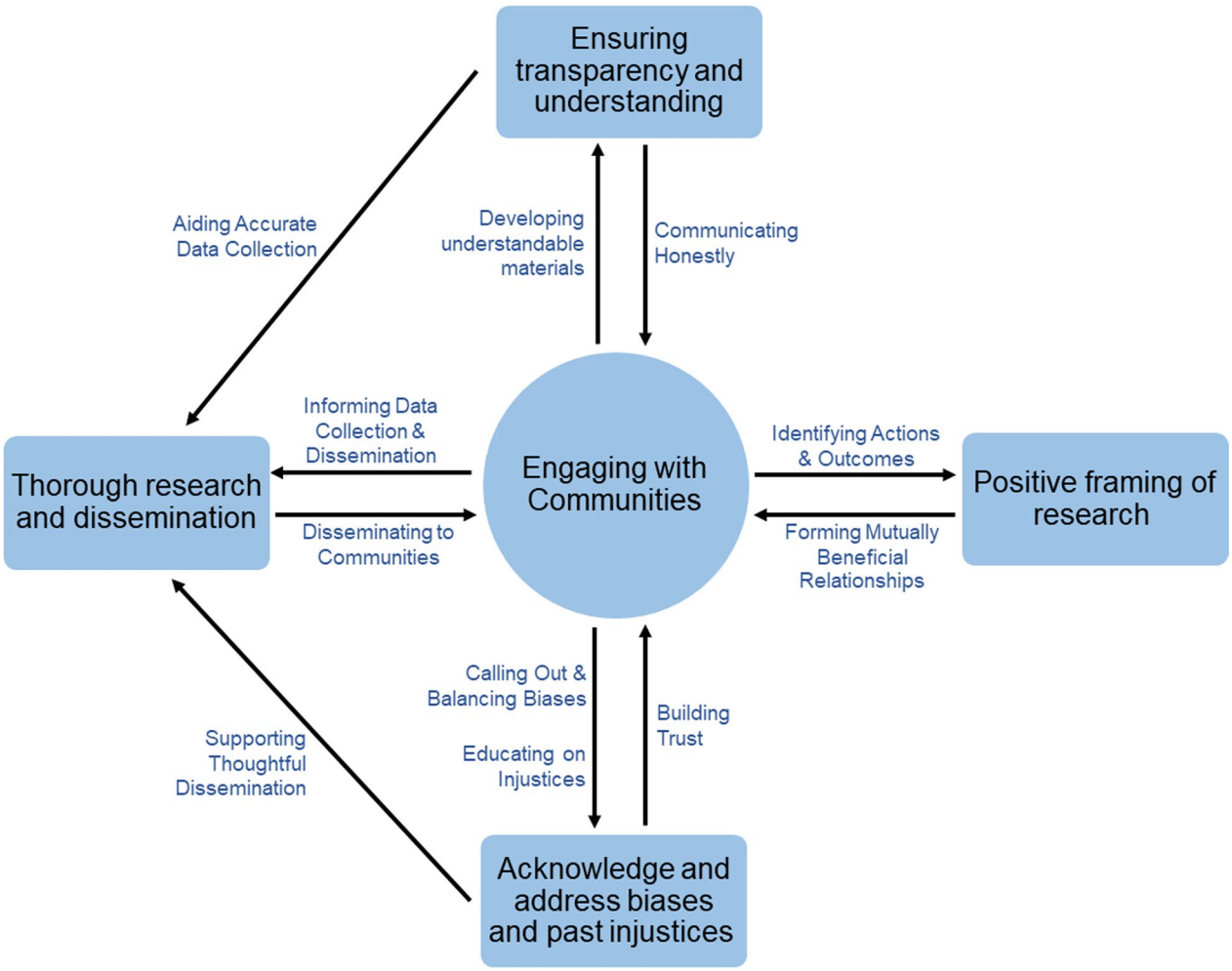

Fig. 1 Participant recommendations to maximize benefit and minimize harms of social epigenomic research with the centrality of engaging with communities. The diagram shows interconnectedness in ways that each recommendation can be leveraged for actions that support other recommendations

better relationships with vulnerable communities can be both a strategy and an outcome and is best accomplished with flexibility, humility, financial support for community involvement, and when the community is engaged in all steps from research design to dissemination and translation into practice [47, 48].

It's worth noting that the recommendation to ensure transparency and understanding of research processes may require special care and ongoing communication in the context of sensitive social epigenomic research and vulnerable populations [29, 38]. Furthermore, the recommendation to recognize and address biases may be most salient with vulnerable populations. One of the more novel recommendations, to positively frame research findings, reminds us that the way we talk about our research and the communities studied matters as do actions to move research findings toward policy and practice that brings positive change. The research community must be cognizant of this and be involved in efforts to ensure that the onus for actions toward changing social determinants of health implicated by research does not fall on vulnerable communities, but on societal structures tasked with supporting individuals and communities [5]. This can be supported both by advocating for evidence-based policies that may emerge from social epigenomic research, partnering with community leaders to affect change in policy and practice, and by integrating implementation science frameworks and collaborations into research [49]. Finally, related to thorough research and dissemination, while researchers do not have direct control over all the ways that their research may be utilized or reported in lay media, researchers have a key role in not overstating study findings and ensuring study limitations are clear. Given the complexity of the social

and genetics milieu in which social epigenomics takes place, discussion has ensued on the feasibility to fully operationalize biosocial views of health into epigenetic experiments [41, 42]. Therefore, careful dissemination that recognizes these limitations is needed and sharing to relevant communities can also support accurate sharing and education about findings directly to those who may be impacted and organizations that may support change based on findings [48].

This study's strengths lie in the multiple methods and study groups, as well as the use of interviews and focus groups for in-depth exploration of topics. Yet, both the qualitative interview and focus group methods are exploratory. Studies assessing the reported perspectives and recommendations in larger samples and with quantitative methods are needed. The study was also conducted with participants from a single metropolitan area in the central USA. Attitudes for B/AA populations in different geographical locations may differ. Finally, a focus on the B/AA population was spurred by the existing social epigenomic study occurring at our institution that was exclusively enrolling B/AA children. We recognize that the benefits and risks of social epigenomic research may be perceived differently in other vulnerable communities and additional studies are needed to include other populations.

Conclusions

This study provides an exploration of attitudes about social epigenomic research in the B/AA population, which may be particularly vulnerable to potential individual and group harms in research linking experiences to epigenetic modifications and health. Study participants saw potential benefit for B/AA communities from social epigenomic research and appreciated studies relevant to B/AA populations, but many felt that their community would be the last to benefit from the research and more likely to suffer harms. Participants gave multiple recommendations of ways that researchers could shift the balance to reduce the risk of harm including addressing biases and injustices, ensuring transparency and understanding, positive framing of research findings, thorough research and dissemination, and engaging communities. Following these community recommendations will improve the quality of social epigenomic research and support ethical conduct, while maximizing benefits and minimizing harms, particularly for vulnerable and historically marginalized communities.

Abbreviations

B/AA	Black and African American
USA	United States of America
SEA	Stress, Epigenomics, and Asthma
EMR	Electronic medical record
ED	Emergency department

Supplementary Information

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Additional file 1

Additional file 2

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Author contributions

CB contributed to study design, led data collection and analysis for all study components, and drafted the manuscript, TB contributed to the design and conduct of recruitment and data collection for all study components and analysis of qualitative data, ABE, SDY, and DL contributed to the design, conduct, and interpretation of focus groups, KF collected data and conducted statistical analyses retrospectively comparing participants and decliners, MM and TP contributed to study design, EG contributed to study design and integration with the SEA study. All authors revised the manuscript and approved the final version for submission.

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Availability of data and materials

The data generated and/or analyzed during the current study are not publicly available due to the potential to identify participants from the raw data. However, data are available from the corresponding author under reasonable request.

Declarations

Ethics approval and consent to participate

This study was approved by the Children's Mercy Kansas City IRB as protocol STUDY00002418. The study was determined to qualify for an Exempt Determination under 45 CFR 46.104 (d) category 2(ii), 4(iii).

Competing interests

The authors declare that they have no competing interests.

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