I, Andrea M Murad, hereby submit this original work as part of the requirements for the degree of Master of Science in Genetic Counseling.

It is entitled:
A Qualitative Study of Adolescents’ Understanding of Biobanks and Their Attitudes Towards Participation, Re-contact and Data Sharing

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A Qualitative Study of Adolescents’ Understanding of Biobanks and Their Attitudes
Towards Participation, Re-contact and Data Sharing

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by

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Abstract

Purpose

While the inclusion of children and adolescents in biobanks is considered in the literature, there is very little information about how adolescents themselves view participation in biobanks and the issues of consent, re-contact and data sharing.

Methods

One investigator (AM) conducted semi-structured, in-person qualitative interviews with adolescents between the ages of 15 – 17 years old in November and December 2014. Adolescents were recruited through the Teen Health Clinic at Cincinnati Children’s Hospital Medical Center’s (CCHMC’s) Burnett Campus and through flyers posted throughout the Medical Center’s Burnett Campus and information posted on CCHMC’s public website and social media pages. Enrollment was continued until data saturation was reached. All interviews were audiotaped and transcribed. Two investigators (AM and RF) coded and analyzed the transcripts using ATLAS.ti software. All the investigators reviewed any discrepancies and resolved them by consensus.

Results

Eighteen interviews were conducted before saturation was reached. Four participants (22%) reported having previously heard of a biobank and 9 (50%) misunderstood what a biobank is even after being provided education. Benefits of enrolling in a biobank identified by participants included contributing to scientific research and helping other’s (89%), learning about their own health (22%), and helping themselves (11%). When asked about risks, 7 participants (39%) were unable to identify any potential risks, 9 participants (50%) identified technical errors, and 7 participants (39%) mentioned loss of privacy. The majority of participants (13, 72%) indicated that they would agree to participate in a biobank if asked. Sixteen participants (89%) felt that individuals who were too young to participate in the decision to enroll in a biobank should be re-contacted at the age of majority, and 13 participants (72%) believed that individuals who assented to participate in the biobank should be re-contacted at the age of
majority. Four (22%) participants were comfortable sharing data from individuals who were too young to participate in the decision to enroll in a biobank and 10 (56%) felt comfortable sharing data of individuals who were able to assent ($\chi^2 = 4.00, p = 0.046$).

**Conclusion**

Few adolescents interviewed had heard of biobanks and many of them had misconceptions about biobanks that persisted even after attempts at educations. These results may indicate a need for better education prior to requesting assent. Adolescents tended to have positive attitudes toward scientific research and perceived few, if any, risks to participation. The majority was willing to participate. Adolescents’ emphasized the importance of individuals being aware of and participating in decisions about biobank participation. They consistently believed that individuals who were unable to assent should be contacted when they reached the age of majority and that their samples and data should not be shared prior to this time. Their opinions about contact and data sharing diverged more when discussing individuals who had previously given assent. These results suggest that research on deidentified data without participants’ knowledge or assent may undermine adolescents’ trust in the research enterprise.

**Key Words:** Biobanking, Adolescents, Consent, Re-contact, Data Sharing, Research
Acknowledgements

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Introduction

Given the expansion of research questions that require large numbers of human specimens and associated data, biobanks have become much more prevalent. Some of the increase in biobanks may be due to advances in bioinformatics and genomics that have made this research possible at a lower cost. While there is no single, widely accepted definition of a biobank, most definitions state that biobanks are repositories of biological samples and linked data collected for future research [1, 2]. Biobanks may include left-over biological samples that were collected for clinical testing as well as those samples that were collected specifically for research purposes. Biobanks are an important resource for advancing personalized medicine because biobanks are an efficient and economical approach to obtaining a large number of samples and data [3]. There are many ethical concerns surrounding biobanks including whether biobanks should be conducted as human subject research, how to obtain informed consent for future research, and whether or not research results and incidental findings should be returned to participants [3-5].

Many biobanks include samples and data from minors. Henderson et al., for example, found that 44% of U.S. biobanks include specimens and data from individuals under the age of 18 [2]. When pediatric populations are included in a biobank additional challenges arise including re-consent and data sharing. When the participant reaches the age of majority, parental permission may no longer valid for the continued research with the participant’s samples and data and it may be necessary for the now adult participant to provide informed consent [6]. Consenting participants who have become adults is often considered to be logistically impracticable and prohibitively expensive [7]. There are also concerns about sharing a participant’s data prior to the age of majority. Gurwitz et al., for example, state that a DNA
donor’s privacy can never be completely ensured within biobanks and argue that DNA samples and data from minors should not be shared with investigators at other institutions until the participants have reached the age of majority and have given informed consent [4].

Additionally, while individuals and groups have analyzed the ethical and logistical issues of including children in biobanks, there is very little information about how children and adolescents themselves view participation in biobanks and the issues of consent, re-contact and data sharing. Hens et al. is one of the only relevant studies. The investigators conducted five focus groups with adult participants and five focus groups with teenage participants to investigate public opinions on the storage and use of tissue samples from minors for research. They found that adolescents placed a large amount of trust in the parents’ to make choices for them. The adolescents thought that the parents were the most suitable persons to make the decision about enrollment in research for them. Furthermore, the investigators found that both adolescents and adults agreed that contacting participants when they reached the age of majority to provide informed consent was a best practice [8].

The objectives of this study were to gain an understanding of adolescents’ familiarity with biobanks, perceptions of the benefits and risks of participating in a biobank, their willingness to participate, their opinions regarding re-contact at the age of majority, and their thoughts about data sharing. Increased understanding of adolescents’ attitudes and beliefs can help guide policy development.
Materials and Methods

Participants and study procedures
Adolescents between the ages of 15 – 17 years old were eligible to participate in semi-structured, in-person interviews. Investigators recruited a convenience sample of adolescents through the Teen Health Clinic at Cincinnati Children’s Hospital Medical Center’s (CCHMC’s) Burnett Campus and through flyers posted throughout the Medical Center’s Burnett Campus. Recruitment information was also posted on CCHMC’s public website and Facebook and Pinterest pages. CCHMC is a freestanding, quaternary care children’s hospital in Cincinnati, Ohio. The Teen Health Clinic serves a primarily female (approximately 66%) and African American (approximately 66%) population. The clinic also includes a program for transgender patients. The clinic has roughly 13,200 visits per year. An estimated 30% of its patients are between 12 – 15 years old and 42% between the ages of 16 – 18 years old. Interviews were conducted from November 1 to December 31, 2014. Enrollment was continued until data saturation was reached. A waiver of consent was granted by CCHMC’s Institutional Review Board. All participants were given a monetary incentive of $20.00 for their participation in this study.

Measures
The investigators created the initial interview guide which had three main sections: prior awareness of biobanks and attitudes towards participation in biobanks; opinions about parental permission, assent and consent; and attitudes towards data sharing (Appendix 1). The guide included relevant education in each of the sections using visual aids (Appendix 2). For the purpose of this study a biobank was defined as a collection of biological samples and health information that are stored and used for research. Participants were informed that, for individuals under the age of 12 years old, only parental permission is needed for the child’s samples to be
included in a biobank while, for individuals between the ages of 12 to 17 years old, the parent must give permission and the teenager assent for the teenager’s samples to be included in the biobank. Open-ended questions were followed up with more directed probes as appropriate to solicit clarity or more in-depth responses. For example, the interviewer initially asked participants to identify benefits and risks of participating in a biobank and then probed about the potential loss of privacy if participants were unable to identify any risks. The interview guide was evaluated for face validity and pretested. One investigator (AM) conducted all interviews. The investigators modified the interview guide and visual aids based on preliminary data suggesting that participants did not understand what a biobank is. In addition, after 7 interviews had been completed the interviewer began to use the teach-back method in order to better determine the participants’ level of understanding[9].

_Data Analysis_

All interviews were audiotaped and transcribed. Two investigators (AM and RF) coded and analyzed the transcripts using ATLAS.ti 7.5.2 software (ATLAS.ti GmbH). Codes were developed based on the literature and review of the transcripts by all investigators[10]. As new codes were developed, previously coded transcripts were reanalyzed. Once the codebook (Appendix 4) was finalized, both AM and RF coded the same transcript independently and compared results. They discussed any discrepancies and reached consensus. They then independently coded 2 more transcripts before comparing their results. Again, any discrepancies were discussed and consensus was reached. They then independently coded the remaining transcripts and compared their results after all coding was complete. Any remaining discrepancies were reviewed by all of the investigators and consensus was reached.
We compared participants’ opinions regarding re-contact and data sharing prior to the age of 12 years vs. between the ages of 12-17 years. Statistical significance was evaluated using the chi-squared test and a p-value of < 0.05 was considered significant.

Results

The investigators enrolled 18 participants before data saturation was reached. The participants’ average age was 16.6 years (SD = 0.81). Grade levels in school ranged from 9th to 12th. The race of the participants is as follows: Caucasian 8 (44%), African American 6 (33%), bi- or multi-racial 3 (17%) or unspecified other 1 (6%). Only one participant (6%) identified as Hispanic; the remaining 17 participants (94%) identified as non-Hispanic. Just over half of the participants (11, 61%) identified as female and 7 (39%) identified as male.

Few participants (4) had previously heard of the term biobank and many did not have a good understanding of what a biobank is even after being provided education. The most common misconception among the participants was that biobanks are blood or tissue banks. For example, one participant (45V) stated, “Like, if someone has, like, a surgery, they need or they need extra blood or they lose blood. You know, like, if the person could go find it for a match.” Some of these misconceptions persisted even after the interviewer tried to correct misunderstandings about biobanks (Table 1).

Risks and Benefits

Overall, participants felt there were significant benefits to participating in a biobank and few, if any, risks. The participants identified a variety of benefits and risks of participating in a biobank (Table 2). Helping others by contributing to scientific research was a major theme. For example, one participant (27B) stated “I don’t see any harm in it. Why not? If it is going to help
research and cure disease someday that might be pretty cool that my blood or urine helped that.” Some participants’ understanding of the research process was in fact relatively sophisticated. Several noted the importance of healthy controls. For example, a participant (31F) stated “I feel like if I were to participate in a biobank, well I would only have healthy samples to give them, but it would be good because it would give them good control to see like how um different treatments react in healthy individuals.” Several participants exhibited the therapeutic misconception that the purpose of the biobank was their medical benefit rather than research. One participant (23Q) stated, “It could help me like learn about the things that are wrong with me or that are not wrong with me, then they could help other people.”

In terms of risks, 8 participants (44%) did not spontaneously identify any risks. One participant (07F), for example, stated, “I honestly don’t see any [risks].” Risks that were mentioned included access by law enforcement and misuse of samples. One participant (45V), for example, stated “… like what if I get in trouble with the law and they like find your blood and something and they are like oh this is the person and then they have contact and stuff.” Many participants (9, 50%) identified technical errors within the biobank, e.g., spilling, contaminating, or mislabeling samples, or samples going bad or not being used, as a major risk. For example, one participant (27B) stated “[A risk is] maybe the samples going bad…spoil[ing], not being able to be used.”

Few participants (4, 22%) spontaneously identified loss of privacy as a risk. Only 3 additional participants identified this as a risk after direct probing. When asked, most participants simply stated that they were not concerned with a loss of privacy. Several, however, mentioned the possibility of identity theft. For example, in response to the question “Some other people have mentioned the risk of losing some of their privacy. Is this something that you would be
worried about?” participant 20A stated “yea that too because that’s your blood. Someone else uses it has your name on it then they can steal your identity I guess.”

**Participation**

The majority of participants (13, 72%) indicated that, if they were asked, they would participate in a biobank. Only 1 participant would decline due to the physical pain of getting blood drawn. When the interviewer clarified that the biobank utilized leftover samples and did not require him to have additional blood drawn, the participant agreed to participate. Some participants expressed uncertainty (4, 22%). Their concerns included having too much blood drawn or having a surgical procedure to obtain the sample. Some participants indicated that they would want more time before making a decision (2, 11%).

**Re-contact at the Age of Majority**

Nearly all participants (16, 89%) believed that individuals who were too young to participate in the decision to enroll in a biobank should be re-contacted at the age of majority (Table 3). However, opinions about what age was the appropriate age for individuals to be included in the decision to enroll in a biobank varied and ranged from 8 to 15 years old. The reasons given included the right to provide their own consent as an adult, potential disagreement with their parents’ decision, the increased ability to understand what a biobank is or what it means to participate in a biobank, and the importance of knowing that they had been enrolled. One participant (31F), for example, stated, “…that is mostly just because the principle, like my parents agreed, I didn’t agree. It would be just like I wasn’t informed. Like I did not know that this happened and that would just bother me a little bit…Like this happened, I was not aware of it, I was not informed about it…I didn’t consent to it. It wasn’t my choice.” Additionally, 4 (22%) of the participants felt that individuals who are too young to provide assent for
participation should be re-contacted at the age of majority because of the possibility that they may have changed their mind. A minority of participants (2, 11%) believed it was not necessary to re-contact participants at the age of majority. Their reasons included: trust in parental decisions or the adequacy of prior parental permission, the difficulty of contacting participants, and the irrelevancy of contact because of the passage of time.

When asked if an individual who assented to participate in a biobank should be re-contacted at the age of majority, again most participants believed that they should be re-contacted (Table 3). The primary justification was that they might have changed their mind. One participant (17C), for example, stated, “Because … now that you’re an adult you might want to make a different choice or you might just want to make a different decision on it.” Other reasons included participants’ right to give their own consent and adults’ greater understanding of biobanks and participation in biobanks. Several individuals stated that the need to re-contact depends on how old the participant was when they gave assent. These participants appeared to believe that, if the individual was close to reaching the age of majority when assent was provided, there was less of a need to re-contact them at 18. One participant (31F) suggested that adolescents should be asked whether or not they wished to be contacted when they turned 18 years old. Finally, 2 participants (11%) stated that re-contact was not necessary. In addition to it being too difficult and the adequacy of the prior assent, one stated that it was the participant’s responsibility to contact the biobank: “…I mean if you are under 18 and its…you will be 18 in a few months I feel like you would remember something like that so you if you didn’t want it there they should just give you their number and you can call (40V).”

When asked what should be done with the samples and health information if the biobank was unable to re-contact participants once they reached the age of majority, the participants’
opinions varied. Half (9, 50%) believed that they should be disposed of or set aside. One participant stated “I think that….maybe they shouldn’t use it anymore because um, they had your consent at one point but they're, like the person is 18 now (09A).” A minority (4, 22%) felt that it was acceptable to continue to use the samples even if the biobank was unable to reach the participant once they reached the age of majority. One argument in support of this position was that it was the responsibility of participants to contact the biobank to withdraw their consent. Two participants both argued that samples from healthy participants should be disposed of and that “really rare sample[s] (31F & 23Q)” could be retained.

The participants who believed that the samples and information should be destroyed had varied opinions of the amount of time the biobank should try to contact participants. Some participants suggested that the biobank should try to contact participants for a certain length of time, from one week to one year, before destroying the samples. Other participants suggested that the biobank should try to contact participants a specific number of times, e.g., 1 time, before destroying the samples.

The interviewer probed the acceptability of continuing to use samples and data if they were deidentified. Half of participants (9, 50%) indicated that this would not be acceptable. Many of these individuals expressed the concern that if the key were destroyed, this would either result in errors or the inability to return results to participants.

Data Sharing
While the majority of participants (10, 56%) felt comfortable with sharing the data of participants who had given assent, less than half (4, 22%) felt comfortable with data sharing for individuals unable to assent (Table 3) ($\chi^2 = 4.00$; 1 degrees of freedom; p = 0.046). Some participants expressed the concern that sharing data of children under 12 was much more
dangerous because these participants were so young and may not be aware that their samples and data were included in a biobank. One individual stated

Like when you are 13 you have, your brain is more open to the things and know what’s goin’ on. When you are younger I feel like…you’re super gullible, even though people my age you still are but you are really gullible because you believe a lot of things and you never know how your safety is enforced with it neither. What if it gets into like the wrong hands or somebody and when they get older and something happens and like they have your DNA (45V).

Adolescents believed themselves capable of providing assent to data sharing.

Many participants expressed trust in the biobank’s policies and procedures. For example, participant 07F stated “Um, as long as it is on professional authorized ground and it is going to another medical professional. As long as it is not going to a third party source or something that can’t be trusted.” They also expressed a concern with waste and inefficiency. One participant stated, “Like I don’t want it to go to waste. That’s the only thing I don’t want. I want it to be used for something (19E)” and another “Like if I put a sample in the biobank here and then someone else somewhere else needed it, I could go there and give it to them also but it would be a waste of time (14A).”

**Discussion**

Overall, we found that: 1) very few adolescents had previously heard of biobanks and many of them had misconceptions about biobanks that persisted even after attempts at education; 2) most of the participants had positive attitudes toward scientific research, were unconcerned with a potential loss of privacy and were willing to participate in biobank research; 3) participants emphasized the importance of individuals being aware of and participating in decisions about biobank participation; and 4) participants consistently believed that individuals
who were unable to assent should be re-contacted when they reached the age of majority and that their samples and data should not be shared prior to this time.

Misunderstandings about the purpose of biobanks persisted throughout the interviews, suggesting that adolescents may have insufficient knowledge to make informed decisions about participation. Other studies have also found that the general population has limited knowledge and understanding of biobanks [11-14]. Ormond et al., for example, found that approximately half of the participants enrolled in a biobank were unaware that their DNA would be stored [14]. Klima et al. found similar results. In a study of 252 individuals who completed the Quality of Informed Consent assessment to measure understanding, they found that less than 40% of participants answered questions correctly about the use of leftover samples, the main study purpose, indefinite storage of samples, risks and harms of biobank participation, receipt of research results and payment of care due to injury from research [13]. These results suggest a need for improved education as part of the informed consent process. Recent studies aimed at improving the informed consent process have found that using a variety of visual and auditory formats may result in a more comprehensive understanding for participants [15, 16].

While some individuals have proposed deidentifying samples and data and conducting biobank research as non-human subjects research [3], our research demonstrated that adolescents’ want to be informed and involved in the decision to participate in a biobank. These findings are similar to results of studies in adult populations. Murphy et al., for example, conducted a survey of a large, representative sample of adults and found they wanted ongoing choices and control over access to their samples and data [17]. A non-human subjects approach would appear to conflict with these expectations and might run the risk on engendering distrust. It is possible that
our participants’ responses were based on misunderstanding of deidentification. In this case, substantial education would be required to obtain participants’ reflective opinion.

While the participants wanted to be aware of the research, they were generally very supportive of it. Only 1 of the 18 participants in this study indicated that if asked, they would not be willing to participate in a biobank. These findings are consistent with previously published studies that found that the majority of the public expresses favorable attitudes towards participating in biobanks and scientific research [18-20]. For example, Kaufman et al. conducted a survey with 4,659 U.S. adults and reported that 60% of participants would participate in a biobank if asked and 92% would allow academic researchers to use study data [20].

While previously published literature has found that individuals rank concerns over privacy issues highest among the potential risks [20-22], very few adolescents in our study identified loss of privacy as a risk to participating in a biobank even after directly being asked if they would be concerned about the potential for loss of privacy. For example, Burstein et al., conducted a study to investigate the differences in data sharing preferences between parents of pediatric patients and adult patients and found that more than half of all participants expressed concern about the potential for loss of privacy [21]. Additionally, in our study the few participants who did identify loss of privacy as a potential risk of participation in a biobank associated loss of privacy with identity theft. This concern may be corrected through further education.

With respect to data sharing and re-contact at the age of majority, our participants tended to treat children who were unable to provide assent differently from those who were. They tended to be less willing to share data and more willing to require re-contact of children who
were unable to provide assent at the time of initial enrollment. These findings are consistent with the results from a previous study that conducted focus groups with teenagers [8] and deviate from Gurwitz et al.’s restrictive recommendation [4]. Biobanks vary in their use of verbal and written assent [23]. Further research would be needed to determine if adolescents perceive requiring their written assent as being more respectful of their desire to participate in decisions affecting them.

Our study has several limitations. The small sample size and recruitment from a single healthcare institution may limit the generalizability of the results. While only 1 of the participants indicated that he/she had an underlying medical condition, healthy adolescents may have been under sampled. In addition, the voluntary nature of participation creates the possibility that the participants may have been positively biased towards participation in research. The recruitment process did not permit the calculation of a response rate or a comparison of participants with nonparticipants. Finally, it was not possible to determine how many of the participants were previously seen at CCHMC and had been asked to participate in its biobank due to recruitment methods.

Conclusions

In spite of the use of verbal, written and visual forms of education, participants exhibited fundamental misunderstandings of the nature and purpose of biobanks. This suggests that assent may not be adequately informed and improved educational methods are needed. While the adolescents in this study had positive attitudes towards biobanks, they emphasized the importance of awareness and participation. This suggests that conducting biobank research as nonhuman subject research could undermine patients’ trust in health care and biomedical
research. Adolescents also tended to see themselves more like adults and younger children as vulnerable and in need of additional protections.

**Disclosure**

The authors declare no conflict of interest.
## Tables

### Table 1 – Misunderstandings of biobanks

<table>
<thead>
<tr>
<th>Theme</th>
<th>Example</th>
<th>N</th>
</tr>
</thead>
</table>
| Blood/Tissue bank   | “It’s [biobank] a place where you can go and have a whole bunch of blood samples or urine samples or sperm samples or egg samples or any bio kind of material…where you can have it held in large quantity…for bettering other people’s lives, like so that they can use it for people who need it.” (17C)  
“Someone else can be losing blood and need some…they can just use mine.” (41I) | 9  |
| Own patient care    | “Um, but um, I guess with blood maybe it can make things easier figuring if, uh, if you have cancer through that way, like through the blood.” (40C)  
“They may find some stuff I didn’t know I had in my blood. Maybe molecules or anything that is floating around in it.” (20A) | 6  |
| Fundraising         | “Uh, raising money and basically fundraising…raising money to help find cures.” (12B)                                                                                                                                  | 1  |
## Table 2 – Benefits and risks of participating in a biobank

<table>
<thead>
<tr>
<th>Theme</th>
<th>Example</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Benefits of participating</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Help other’s/Contribute to</td>
<td>“I feel it wouldn’t hurt to help because you know if it can help somebody else then you know it is, it’s just, it’s cool to help.” (15E)</td>
<td>16</td>
</tr>
<tr>
<td>scientific research</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Learn about own health</td>
<td>“Some of those benefits could be like finding the risk you have later in life…or not even knowing that you were looking for something but finding it anyways.” (21A)</td>
<td>4</td>
</tr>
<tr>
<td>Help self</td>
<td>“Um, cuz like it could help me out if I like have a disease and then they’ll know how to cure it.” (23Q)</td>
<td>2</td>
</tr>
<tr>
<td><strong>Risks of participating</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Technical errors</td>
<td>“Maybe if it was unsanitary…I mean if they have all these samples of something they don’t wanna get them mixed up or contaminated.” (17C)</td>
<td>9</td>
</tr>
<tr>
<td>Loss of privacy</td>
<td>“Uh, all your stuffs out, all your DNA’s out there.” (14A)</td>
<td>7</td>
</tr>
<tr>
<td>Physical risk</td>
<td>“Pain. Uh, they gotta put a needle in you and suck, and pull blood outta your skin and stuff like that. Pain.” (41I)</td>
<td>4</td>
</tr>
<tr>
<td>Misuse of samples</td>
<td>“Or maybe um some sort of evil plot maybe….like maybe um developing new drugs that are used for execution possibly.” (31F)</td>
<td>3</td>
</tr>
<tr>
<td>Incidental findings</td>
<td>“Cuz you might find some unexpected thing such as diseases in the blood.” (20A)</td>
<td>2</td>
</tr>
<tr>
<td>Harm to others</td>
<td>“There could be something that goes wrong and…they mix something up and is somehow gets injected into someone or something happens and you put someone else at risk for something.” (21A)</td>
<td>1</td>
</tr>
<tr>
<td>None</td>
<td>“I don’t really think that there is any [risk].” (19E)</td>
<td>8</td>
</tr>
</tbody>
</table>
Table 3 – Re-contact and data sharing

<table>
<thead>
<tr>
<th>Re-contact and Data Sharing</th>
<th>Theme</th>
<th>N</th>
<th>(%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Re-contact for children under 12 years old</td>
<td>Yes</td>
<td>16</td>
<td>(89)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>2</td>
<td>(11)</td>
</tr>
<tr>
<td>Re-contact for individuals between 12 to 17 years old</td>
<td>Yes</td>
<td>13</td>
<td>(72)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>2</td>
<td>(11)</td>
</tr>
<tr>
<td></td>
<td>Depends</td>
<td>3</td>
<td>(17)</td>
</tr>
<tr>
<td>Data sharing for individuals under 12 years old</td>
<td>Yes</td>
<td>4</td>
<td>(22)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>4</td>
<td>(22)</td>
</tr>
<tr>
<td></td>
<td>Depends</td>
<td>8</td>
<td>(44)</td>
</tr>
<tr>
<td></td>
<td>Don’t know</td>
<td>2</td>
<td>(11)</td>
</tr>
<tr>
<td>Data sharing for individuals between 12 to 17 years old</td>
<td>Yes</td>
<td>10</td>
<td>(56)</td>
</tr>
<tr>
<td></td>
<td>No</td>
<td>1</td>
<td>(6)</td>
</tr>
<tr>
<td></td>
<td>Depends</td>
<td>7</td>
<td>(39)</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Re-contact and data sharing based on age</th>
<th>&lt; 12 years old</th>
<th>12 – 17 years old</th>
<th>p-value</th>
</tr>
</thead>
<tbody>
<tr>
<td>Re-contact at age of majority</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>16</td>
<td>13</td>
<td>0.846</td>
</tr>
<tr>
<td>No</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Data sharing</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>4</td>
<td>10</td>
<td>0.046</td>
</tr>
<tr>
<td>No</td>
<td>4</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Demographics of participants</td>
<td>Characteristic</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>------------------------------</td>
<td>------------------------------------</td>
<td>----</td>
<td>----</td>
</tr>
<tr>
<td>Gender</td>
<td>Male</td>
<td>7</td>
<td>40</td>
</tr>
<tr>
<td></td>
<td>Female</td>
<td>11</td>
<td>61</td>
</tr>
<tr>
<td>Race</td>
<td>Black/African American</td>
<td>6</td>
<td>33</td>
</tr>
<tr>
<td></td>
<td>White/Caucasian</td>
<td>8</td>
<td>44</td>
</tr>
<tr>
<td></td>
<td>Two or more/Other</td>
<td>4</td>
<td>22</td>
</tr>
<tr>
<td>Age</td>
<td>15</td>
<td>4</td>
<td>22</td>
</tr>
<tr>
<td></td>
<td>16</td>
<td>9</td>
<td>50</td>
</tr>
<tr>
<td></td>
<td>17</td>
<td>5</td>
<td>28</td>
</tr>
<tr>
<td>Theme</td>
<td>Example</td>
<td>N</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------</td>
<td>-------------------------------------------------------------------------</td>
<td>---</td>
<td></td>
</tr>
<tr>
<td><strong>Re-contact for under age 12 years</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Yes</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Give own consent</td>
<td>“Because at that, at that age, at age 12 you couldn’t, you had no say so over what, you had no say so.” (41I)</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Disagree with parent</td>
<td>“I feel like little kids wouldn’t want to do the stuff, like their parents would make them.” (11B)</td>
<td>8</td>
<td></td>
</tr>
<tr>
<td>Older now</td>
<td>“Cuz I’m gonna be old enough to handle my own, be responsible for my own stuff since I’m 18.” (17C)</td>
<td>6</td>
<td></td>
</tr>
<tr>
<td>Make aware of participation</td>
<td>“Um, because when you turn 18 you should be notified about the parents, the decision your parent made for you prior to your knowledge.” (27B)</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>Changed mind</td>
<td>“You could have changed your mind…” (14A)</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td><strong>No</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No longer relevant</td>
<td>“Um, honestly by the amount of time that has gone by I don’t think that it would be relevant anymore.” (07F)</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td><strong>Re-contact for 12 – 17 years old</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Yes</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Changed mind</td>
<td>“Um, yes. I feel as if my opinions on it could change when I get older.” (42C)</td>
<td>10</td>
<td></td>
</tr>
<tr>
<td>Reminder</td>
<td>“Because it’s still your choice and they should remind you…” (09A)</td>
<td>4</td>
<td></td>
</tr>
<tr>
<td>Give own consent</td>
<td>“I don’t want to feel like I am forced into doing it so to have the option again when I am 18 might be helpful.” (19E)</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>No reason not to</td>
<td>“Uh, yeah sure, I mean…I don’t see why not.” (07F)</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td><strong>No</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant’s responsibility</td>
<td>“No, you should know that you are in a biobank and what goes and…they shouldn’t have to like call you again cuz you were like there…if you want to change your mind then you can call them if you want it token out cuz you know that it is in there and what it is for.” (45V)</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Consent already given</td>
<td>“Well because I already agreed to it. Like my actual self already agreed to it, it wasn’t someone agreeing on my behalf. I already agreed.” (31F)</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Depends</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What participant wants</td>
<td>“I mean like I think it could probably be a personal preference so they should probably just ask the same questions ‘Do you want us to call in a few months’.” (40V)</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>When assent was given</td>
<td>“I mean if you are under 18 and its…you will be 18 in a few months I feel like you would remember something like that so if you didn’t want it there they should just give you their number and you can call. If it like from 13 to 18 it is like 5 years. You possibly could have forgotten about that cuz I mean everything that is going on through school and stuff like that.” (40V)</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>
## Supplementary Table 3 – What to do with samples if unable to re-contact

<table>
<thead>
<tr>
<th>What should be done with samples if unable to re-contact at age of majority</th>
<th>Theme</th>
<th>Example</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>What to do if unable to re-contact</td>
<td>Destroy samples</td>
<td>“Um how ever they dispose of old materials and you know old DNA samples and stuff like that. How ever they get rid of them probably, then just do that.” (22J)</td>
<td>6</td>
</tr>
<tr>
<td></td>
<td>Continue using samples</td>
<td>“I would say they should keep it because it’s already been agreed and unless you say no to it then it is still agreed upon.” (21A)</td>
<td>4</td>
</tr>
<tr>
<td></td>
<td>Stop using samples</td>
<td>“Probably just put it to the side until they get in contact with me.” (15E)</td>
<td>3</td>
</tr>
<tr>
<td></td>
<td>Contact parent</td>
<td>“I think if they can’t get a hold of you maybe they should try to contact a parent or something like that…” (40V)</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>Depends</td>
<td>“Um, I guess it would kind of depend on what kind of sample it is. Like taking into account I guess if it’s a really rare sample that we need, cuz at one point they did have consent for it. But I feel like if maybe it’s just a healthy sample that can just toss that one because I am sure there is plenty of healthy samples around.” (31F)</td>
<td>4</td>
</tr>
</tbody>
</table>
## Supplementary Table 4 – Data Sharing

<table>
<thead>
<tr>
<th>Theme</th>
<th>Example</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Data sharing for under 12 years old</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Contributes to scientific research</td>
<td>“Well, you, sharing information always helps the researchers or people, uh, get a better understanding of what’s going on and it always can help them…” (27B)</td>
<td>2</td>
</tr>
<tr>
<td>Help other people</td>
<td>“Yes, I believe that simply because you could have a similarity in different parts or different, yeah different parts of you know the state, the city, the country, the world wherever. And um, they, you could definitely put the information together and figure out a cure or some kind of slowing agent for that.” (21A)</td>
<td>1</td>
</tr>
<tr>
<td>Trust data sharing policies</td>
<td>“Yes, if they’re like, I don’t know, I guess certified researchers I guess. Not just random.” (19E)</td>
<td>1</td>
</tr>
<tr>
<td>No</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Vulnerable population</td>
<td>“I just feel like since they are under 12 they are too young especially because they don’t even know what’s going on yet.” (42C)</td>
<td>2</td>
</tr>
<tr>
<td>May be unaware of participation</td>
<td>“Um, like they might not know what it was for when they were little and not know where it has been and stuff.” (11B)</td>
<td>2</td>
</tr>
<tr>
<td>Disagree with parent’s decision</td>
<td>“When you are younger they [parents] make the decision and maybe sometimes they are right and sometimes maybe not.” (45V)</td>
<td>2</td>
</tr>
<tr>
<td>Did not give own consent</td>
<td>“Um, they have a couple more years until they are 18 and their samples could already be used and on in the databases for researchers and it is really hard to get back and I feel as if once the child grows up it could make them feel uncomfortable in a way knowing that they didn’t have a say or consent in that.” (42C)</td>
<td>1</td>
</tr>
<tr>
<td>Loss of privacy</td>
<td>“No because what if it get into like the wrong hands or somebody and when they get older and something happens and like they have your DNA.” (45V)</td>
<td>1</td>
</tr>
<tr>
<td>Difficult to get back</td>
<td>“Because probably when they get older and they want it back it’s, it’s impossible to get it back probably…” (20A)</td>
<td>1</td>
</tr>
<tr>
<td>Depends</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Participant’s agreement</td>
<td>“If they’re [participant] comfortable with it or they allowed, their parents allowed [it].” (12B)</td>
<td>4</td>
</tr>
<tr>
<td>Rare/unique sample</td>
<td>“Yeah, if they have something special about them. Like um, like an immunity to something like the common cold.” (23Q)</td>
<td>1</td>
</tr>
<tr>
<td>Specific study</td>
<td>“Um if they have like the biobank from a different organization or institution has special research or study that they would like to follow up on then I think that would be ok…Like new DNA research or...”</td>
<td>1</td>
</tr>
</tbody>
</table>
a new type of disease research for like kids under 12 or anything of that nature.” (22J)

<table>
<thead>
<tr>
<th>Don’t know</th>
<th>“I don’t know about that…I feel it shouldn’t cuz you know they’re young and they’re children…I kinda feel like it’s like their privacy and they’re young…but at the same time I still feel like it should because you know they gave up their samples.” (15E)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Data sharing for 12 – 17 years old</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Yes</strong></td>
<td></td>
</tr>
<tr>
<td>Assent given</td>
<td>“Yeah, cuz they agreed to it…if they read everything about what they agreed to then they should know like um their samples could be transported anywhere.” (23Q)</td>
</tr>
<tr>
<td>Contribute to scientific research</td>
<td>“Well sharing information always helps the researchers or people uh get a better understanding of what’s going on it always can help them.” (27B)</td>
</tr>
<tr>
<td>Trust data sharing policies</td>
<td>“There’d be paperwork of the sample being moved, like of being distributed.” (14A)</td>
</tr>
<tr>
<td>Help other people</td>
<td>“Some researchers might be workin’ on something about trying to stop diseases between that age group so it might be helpful to have children’s samples in that age group and sometimes they might need different researcher to finish their research. Your sample can be a big breakthrough; you know it can help millions of people one day.” (15E)</td>
</tr>
<tr>
<td><strong>No</strong></td>
<td></td>
</tr>
<tr>
<td>Difficult to get back</td>
<td>“Because they might want it back also but they can’t get it back…they had the say so but it doesn’t matter because they might want it back later on down the line.” (20A)</td>
</tr>
<tr>
<td><strong>Depends</strong></td>
<td></td>
</tr>
<tr>
<td>Participant’s agreement</td>
<td>“I think if the participant…maybe they could be asked that question, ‘do you want your to be able to be transferred or not’ should be a question asked and left up to a personal thing…cuz I feel like some people would think that it was just staying here and not really know that it could go off somewhere else. I think that if they are informed that it can go somewhere else and given the choice that maybe would ease their mind when they are 18…” (40V)</td>
</tr>
<tr>
<td>Rare sample</td>
<td>“They could um look at their different charts and see like, if there’s some samples that the other researcher don’t have…or like say if I found someone special like they all could get a little bit of the sample.” (23Q)</td>
</tr>
<tr>
<td>Specific study</td>
<td>“Like that have a certain type of study that they need, yeah I think that would be ok.” (22J)</td>
</tr>
</tbody>
</table>
References

Appendix 1 – Interview Guide

1. Have you ever heard of a biobank before? If no, skip to biobank description. Where did you hear about it?

2. Can you tell me what you know or have heard about biobanks?

3. Have you ever been asked to participate in a biobank? If no, skip to biobank description.

4. Did you agree to participate?
   Why or why not?

(Read by researcher) A biobank is a collection of biological samples and health information that is stored and used in research studies. The samples may include blood or urine and the health information may include demographic information, medical test results, and information about your medical treatment. The samples and health information may be used immediately, stored for a short amount of time, or stored indefinitely. Some of the samples may have been left over from medical tests and some may have been collected specifically to be put in the biobank. Identifying information, such as participants’ names and dates of birth are removed and a code is used to link the samples and health information to the participant. The coded samples and health information are then shared with researchers. Researchers might use it to try to find the cause of a disease or improve treatments. For example, researchers might be interested in studying the genetic and environmental causes of conditions such as asthma or breast cancer. It is important that researchers have samples from both individuals with the disease that they are studying and samples from individuals who are healthy.

5. Take a minute to look this over. Just to help me make sure I am explaining this information accurately, could you tell me in your own words what a biobank is?

6. What do you think are the potential benefits of participating in a biobank?
   That is interesting. Can you tell me more about that?
   One of the potential benefits is contributing to scientific research. Is that important to you?
7. What do you think are the potential risks of participating in a biobank?
   That is interesting. Can you tell me more about that?

   Some people worry about their privacy. Is that something that you would be worried about?

(Read by researcher) Participation in the biobank is voluntary. This means that people do not have to let their samples and health information be put in the biobank. It also means if they do agree to participate in the biobank, they can ask for their samples and health information to be removed at any time. For individuals under the age of 12, their parent is asked for permission for their child’s samples and health information to be included in the biobank. For teenagers between the ages of 12 and 17 years old, both the parent and the teenager must give permission for the teenager’s samples and information to be included in the biobank. If the teenager does not agree to participate, even if the parent does, the samples cannot be included. When individuals turns 18 years old they are legally considered adults and are able to make decisions, including decisions about participating in research, for themselves.

8. Take a moment to look this over and let me know if you have any questions about this information?

9. If your parents agreed for you to be in a biobank when you were under 12 years old, should the biobank contact you when you turn 18 so that you can decide for yourself whether you want to continue to participate in the biobank?
   Why or why not?

10. If you were asked to participate in a biobank now, what would you say?
   Why?

11. If you said yes to participating in a biobank now, should the biobank contact you once you turn 18 years old to ask you if you want to continue to participate in the biobank as an adult?
   Why or why not?
12. If the biobank could not get in touch with you once you turn 18 years old, what do you think should be done with your samples and health information?

Would it be alright to continue to use the samples and health information if the code linking them to you was destroyed and it was not possible for the samples and health information to be linked back to you?

Should the samples and health information be destroyed?

(Read by the researcher) When an individual agrees to participate in a biobank, their samples and health information can be used for many different research studies. Researchers who work at the same hospital or institution where the samples and health information were first collected, as well as researchers who work at different institutions, can request to use the coded samples and health information stored in the biobank. This is called data sharing. Most biobanks have committees that make sure that samples and health information are only shared with qualified researchers doing appropriate research. The researchers requesting to use the samples and health information in the biobank sign contracts about how they will use it. Some information is required to be placed in national research databases. Many types of research can only be done by sharing samples and health information. Some people believe that sharing the samples and health information is good. They believe that it is essential for completing research to improve health and that the risks to the participants are small. Potential risks include loss of privacy. Other people think that sharing children and teenagers’ samples and health information is bad because if children or teenager’s decide they do not want to participate in the biobank after they turn 18, it may be difficult or impossible to get the shared samples and information back.

13. Take a moment to look this over and let me know if you have any questions about his information.

14. Do you think that it is ok to share samples from individuals who are under the age of 12 years old with researchers at other institutions?

Why or why not?

15. Do you think that it is ok to share samples from individuals who are between the ages of 12 – 17 years old with researchers at other institutions? Why or why not?
Appendix 2 – Visual Aids

What is a biobank?

- A biobank is a collection of biological samples and health information that is stored and used in research studies.
- The samples may include left over blood or urine.
- Health information may include demographic information, medical test results, and information about your medical treatment.
- The samples and health information may be used immediately, stored for a short amount of time, or stored indefinitely.
- Identifying information, such as participants’ names and dates of birth is removed and a code is used to link samples and health information to the participant.
- The coded samples and health information are shared with researchers.
- Researchers might use it to try to find the cause of a disease or improve treatments.
- It is important that researchers have samples from both individuals with the disease they are studying and individuals who are healthy.

Deciding to participate in a biobank

- Participation is voluntary. This means that people do not have to let their samples and information be put in the biobank. It also means that if they do agree to participate in the biobank, they can ask for their samples and health information to be removed at any time.
- For individuals under the age of 12, their parent is asked for permission for their child’s samples and health information to be included in the biobank.
- For teenagers between 12 and 17 years old, both the parent and the teenager must give permission for the teenager’s samples and information to be included in the biobank. If the teenager does not agree to participate, even if the parent does, the samples cannot be included.
- When individuals turn 18 they are legally considered adults and are able to make decisions, including decisions about participating in research, for themselves.

<table>
<thead>
<tr>
<th>Child’s Age</th>
<th>Parent Agreement</th>
<th>Teenagers Agreement</th>
<th>Adults’ Consent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Under 12 years</td>
<td>☒</td>
<td></td>
<td></td>
</tr>
<tr>
<td>12 – 17 years</td>
<td>☒</td>
<td>☒</td>
<td></td>
</tr>
<tr>
<td>18 years and older</td>
<td></td>
<td></td>
<td>☒</td>
</tr>
</tbody>
</table>
### Data Sharing

- Researchers who work at the same hospital or institution where the samples and health information were first collected, as well as researchers who work at different institutions, can request to use the coded samples and health information stored in the biobank. This is called **data sharing**.

- The researchers requesting to use the samples and information in the biobank sign contracts about how they will use it.

- Some people believe that sharing the samples and health information is good. They believe that it is essential for completing research to improve health and that the risks to the participants are small.

- Other people think that sharing children and teenagers' samples and health information is bad. If children or teenager's decide they do not want to participate in the biobank after they turn 18, it may be difficult or impossible to get the shared samples and information back.
Appendix 3 – Participant Demographic Form

Name: ____________________________________ Date of Birth? _______________________

Gender?
☑ Male
☑ Female

Race? (Please check all that apply)
☑ White
☑ Black or African American
☑ American Indian or Alaska Native
☑ Asian or Pacific Islander
☑ Other ______________________
☑ Don't know or unsure

Are you Hispanic, Latino, or Spanish?
☑ Yes
☑ No
☑ Don't know or unsure

What grade are you in?
☑ 9th
☑ 10th
☑ 11th
☑ 12th

Do you have a chronic health condition?
☑ Yes
☑ No

How many times have you seen a healthcare provider in the last 12 months? ______________

On a scale of 1 to 10 where 10 represents people who have the most money, education and best jobs and 1 represents people who have the least money, education and no job, where would your family be on this scale?

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
<th>10</th>
</tr>
</thead>
<tbody>
<tr>
<td>(Least money)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(Most money)</td>
</tr>
</tbody>
</table>

Is it ok to contact you if I have more questions in the future? ________________

Preferred method of contact (circle one): EMAIL PHONE

Phone number: __________________________ Email address: ________________________________
Appendix 4 - Codebook

Themes/Codes

A. Background information – This theme primarily focuses on participants responses to questions regarding what information they already know about biobanking.

1. Heard of a biobank before – This theme focuses on participants’ responses to question about if they have ever heard of a biobank before.
   a. Yes – Use this code when participants indicate that they have heard of a biobank before.
   b. No – Use this code when participants indicate that they have not heard of a biobank before.

2. Where from – This theme focuses on participants responses to question about where they have previously heard of a biobank; only use these codes if participant has previously answered that they HAVE heard of a biobank before.
   a. From healthcare provider – Use this code when participants indicate that they heard of a biobank before from a physician, nurse or other healthcare provider.
   b. From parent – Use this code when participants indicate that they heard of a biobank from a parent.
   c. From friends – Use this code when participants indicate that they heard of a biobank from friends.
   d. From school – Use this code when participants indicate that they heard of a biobank from a teacher or at school.
   e. Don’t know – Use this code when participants indicate that they do not know or do not recall where they heard of a biobank from.

3. What do you know – This theme primarily focuses on participants responses to the question about what they have heard or what they know about biobanks; Use these codes only when participants indicate that they HAVE heard of a biobank before. These codes are not exclusive; more than one can be applied.
   a. Just the name – Use this code when participants indicate that they have only heard the term or name “biobank” before.
   b. Samples for research – Use this code when participants indicate that they believe a biobank is something where samples are collected and used for research.
   c. Blood Bank – Use this code when participants indicate that they believe a biobank is something where blood is collected to give to people when they need a transfusion.

4. Asked to participate – This theme focuses on participants’ responses to question about if they were previously asked to participate in a biobank; only use this code if participants have previously answered that they HAVE heard of a biobank before.
   a. Yes – Use this code when participants indicate that they have previously been asked to participate in a biobank.
   b. No – Use this code when participants indicate that they have not previously been asked to participate in a biobank before.

5. Did you participate – This theme primarily focuses on participants responses to the questions about whether or not they agreed to participate in a biobank when
they were previously asked. Use these codes only when participants indicate that they HAVE been asked to participate in a biobank before.

a. Participated – Use this code when participants indicate that they agreed to participate in a biobank.

b. Did not participate – Use this code when participants indicate that they did not agree to participate in a biobank.

6. Why/Why not participate – This theme primarily focuses on participants’ responses to the question about why they did or did not agree to participate in the biobank when they were previously asked; Use this code only when participants indicate that they HAVE previously been asked to participate in a biobank. These codes are not exclusive; more than one can apply.

a. For money – Use this code when participants indicated that they agreed to participate in a biobank for the financial incentive offered.

b. To help others – Use this code when participants indicated that they agreed to participate in a biobank because they felt it could help others.

c. To help scientific research – Use this code when participants indicate that they agreed to participate in a biobank because they felt it could further scientific research.

d. To help self – Use this code when participants indicate that they agreed to participate in a biobank because they felt it could help their own health/medical condition.

e. Did not want to – Use this code when participants indicate that they did not agree to participate in a biobank because they did not want to.

f. No benefits – Use this code when participants indicate that they did not agree to participate in a biobank because they felt that there was no benefit to participating.

g. Concern for privacy – Use this code when participants indicate that they did not agree to participate in a biobank because they were concerned about the potential for loss of privacy.

h. Physical risk – Use this code when participants indicate that they did not agree to participate in a biobank because they did not want to be stuck with a needle or were concerned about other physical risks.

B. Benefits – This primarily focuses on what adolescents’ view as benefits to participating in a biobank. These codes may have been referenced by participants throughout their interview. Codes in this category are not exclusive; more than one can apply.

1. Help others – Use this code when participants indicate that participating in a biobank could help other individuals by helping to find cures or treatments for diseases.

2. Promote scientific research – Use this code when participants indicate that participating in a biobank could help contribute to scientific research or the advancement of scientific knowledge.

a. Normal control – Use this code when participants indicate that a benefit to participating in a biobank would be promoting scientific research by contributing a normal control sample.

b. Unique/rare sample – Use this code when participants indicate that a benefit to participating in a biobank would be promoting scientific
research by contributing a sample from an individual with a rare or not well understood condition.

3. Help self – Use this code when participants indicate that participating in a biobank could help their own medical care in the future.

4. Learn about health – Use this code when participants indicate that participating in a biobank could help them to learn more about their own health.

5. No benefit – Use this code when participants indicate that participating in a biobank has no potential benefits.

C. Risks – This primarily focuses on what adolescents’ view as the risks to participating in a biobank. These codes may have been referenced by participants throughout their interview. Codes in this category are not exclusive; more than one can apply.

1. Physical risk – Use this code when participants indicate that there is a physical risk to the participant when participating in a biobank (e.g. risk of blood draw, risk for amount of sample taken, etc.).

2. Loss of privacy – Use this code when participants indicate that there is a potential for loss of privacy or concern about personal information getting into the wrong hands.
   a. Identity theft – Use this code when participants indicate that loss of privacy is a risk to participating in a biobank because of the concern for identity theft.
   b. Law enforcement – Use this code when participants indicate that loss of privacy is a risk to participating in a biobank because of the possibility of future trouble with law enforcement and the concern that law enforcement may gain access to information stored in the biobank.
   c. Sharing personal thoughts – Use this code when participants indicate that loss of privacy is a risk to participating in a biobank because of concerns over sharing certain personal thoughts.

3. Misuse of samples/information – Use this code when participants indicate that there could be a concern that samples and health information in a biobank might not be used to do appropriate research, that samples might be wasted, or that samples might be collected without proper authorization or permission.

4. Technical errors – Use this code when participants indicate that there could be a risk associated with technical problems/mistakes make in the biobank (e.g. not processing samples properly, not storing samples properly, sample contamination within the biobank, etc.).

5. No risk – use this code when participants indicate that they do not feel there is any risk associated with participating in a biobank.

6. Harm to others – use this code when participants indicate that there could be a risk of harm to other people when participating in a biobank.

7. Incidental findings – Use this code when participants indicate that there could be a risk of finding out something about their health that they did not previously know when participating in a biobank.

D. Loss of privacy – This theme primarily focuses on participants’ responses to question about if they would be concerned with a loss of privacy when considering participating in a biobank.
1. Yes – Use this code when participants indicate that they would be concerned about a loss of privacy when considering participating in a biobank.
   a. Distrust of medical professionals/researchers – Use this code when participants indicate that they would be concerned with a loss of privacy because of a lack of trust in the medical profession/medical professionals.
   b. Distrust biobank governance – Use this code when participants indicate that they would be concerned with a loss of privacy because of lack of trust in the policies and procedures that are put in place to ensure proper use of samples within the biobank.
   c. Mistakes might happen – Use this code when participants indicate that they would be concerned with a loss of privacy because information/samples could mistakenly get lost, misplaced or end up in the wrong hands.
   d. Incidental findings – Use this code when participants indicate that they are concerned with a loss of privacy when participating in a biobank because they may find out something about their own health which they did not previously know.

2. No – Use this code when participants indicate that they would not be concerned with loss of privacy when considering participating in a biobank.
   a. Trust in medical professionals/researchers – Use this code when participants indicate that they would not be concerned with a loss of privacy because they trust their doctor/healthcare provider.
   b. Trust in biobank governance – Use this code when participants indicate that they would not be concerned with a loss of privacy because they trust the policies and procedures that are put in place to ensure proper use of samples within a biobank.
   c. Do not see the harm – Use this code when participants indicate that they would not be concerned with a loss of privacy because they do not see what harm could be done if their identity or personal information was known.

E. Re-contact children under 12 at age of majority – This theme primarily focuses on participants responses to question about if the biobank should contact participants once they reach the age of 18 if their parents had consented for them to be in a biobank when they were under the age of 12.
   1. Yes – Use this code when participants indicate that children who were under the age of 12 years old when their parents consented for them to be in a biobank should be contacted at the age of majority to provide their own consent. Codes in this category are not exclusive; more than one can apply.
      a. Right to give own consent – Use this code when participants express that re-contact at age of majority is important so that participants can make the decision to participate as an adult.
      b. May not agree with parents decision – Use this code when participants express that re-contact at the age of majority is important because they individual may not agree with the decision their parent had made for them.
c. Changed mind – Use this code when participants express that re-contact at the age of majority is important because the individual may have changed their mind about participating in the biobank.

d. Participant is older – Use this code when participants express that re-contact at the age of majority is important because the individual is now older and will have a better understanding of what being in the biobank means.

e. Aware of involvement – Use this code when participants indicate that re-contact at the age of majority is important because they want to be aware of their participation NOT because they feel they have a right to give own consent.

2. No – Use this code when participants indicate that children who were under the age of 12 years old when their parents consented for them to be in a biobank should not be contacted for at the age of majority to provide their own consent. Codes in this category are not exclusive; more than one can apply.
   a. Trust parents decision – Use this code when participants express that re-contact at the age of majority is unnecessary because of trust in the decision that their parents had made for them.
   b. Too difficult – Use this code when participants express that re-contact at the age of majority is unnecessary because it will be too difficult to re-contact every single participant.
   c. Consent already given – Use this code when participants express that re-contact at the age of majority is unnecessary because consent was already granted and that consent should be enough.
   d. No longer relevant – Use this code when participants express that re-contact at the age of majority is unnecessary because they feel that it is no longer relevant because the amount of time that has passed or because of other factors.

F. Participation in a biobank now – This theme primarily focuses on participants responses to question about if they were asked to be in a biobank right now, what would they say.

   1. Yes – Use this code when a participant indicates that they would participate in a biobank if they were asked right now. Codes in this category are not exclusive; more than one can apply.
      a. Help others – Use this code when participants indicate that participating in a biobank could help other individuals by helping to find cures or treatments for diseases.
      b. Promote scientific research – Use this code when participants indicate that participating in a biobank could help contribute to scientific research or the advancement of scientific knowledge.
      c. Help self – Use this code when participants indicate that participating in a biobank could help their own medical care in the future.
      d. Learn about health – Use this code when participants indicate that participating in a biobank could help them to learn more about their own health.
      e. Don’t see why not – Use this code when participants indicate that they do not see any reason why they should not participate in a biobank including
because they feel like they can change their mind at any time and ask to be taken out.

2. No – Use this code when a participant expresses that they would not participate in a biobank if they were asked right now. Codes in this category are not exclusive; more than one can apply
   a. Physical risk – Use this code when participants indicate that there is a physical risk to the participant when participating in a biobank (i.e. risk of blood draw, risk for amount of sample taken, etc.).
   b. Loss of privacy – Use this code when participants indicate that there is a potential for loss of privacy or concern about personal information getting into the wrong hands.
   c. Misuse of samples/information – Use this code when participants indicate that there could be a concern that samples and health information in a biobank might not be used to do appropriate research or that samples might be wasted.

3. Don’t Know – Use this code when participants express that they are unsure of whether or not they would participate in a biobank if asked right now. Codes in this category are not exclusive; more than one can apply.
   a. Purpose – Use this code when participants express that it would depend on what the biobank wanted the samples and information for.
   b. What was required of them – Use this code when participants express that it would depend on what was asked of them, how much sample was requested and what type of sample was requested.
   c. Pros vs. Cons – Use this code when the participant indicates that they would just need time to weigh the pros vs. cons of participating in the biobank before they could make a decision.

G. Re-contact adolescents between 12 – 17 at age of majority - This theme primarily focuses on participants responses to question about if the biobank should contact participants once they reach the age of 18 if their parents had assented to be in a biobank when they were between the age of 12 – 17 years old.

   1. Yes – Use this code when participants indicate that individuals who were between the ages of 12 -17 years old when agreeing to participate in a biobank should be contacted at the age of majority to provide consent as an adult. Codes in this category are not exclusive; more than one can apply.
      a. Right to give own consent – Use this code when participants express that re-contact at age of majority is important so that participants can make the decision to participate as an adult.
      b. Changed mind – Use this code when participants express that re-contact at the age of majority is important because the individual may have changed their mind about participating in the biobank.
      c. Participant is older – Use this code when participants express that re-contact at the age of majority is important because the individual is now older and will have a better understanding of what being in the biobank means.
d. No reason not to – Use this code when participants express that re-contact at the age of majority is important because there is no reason for the biobank not to contact them.

e. Reminder – Use this code when participants express that re-contact at the age of majority is important because they would like to be reminded that they are participating NOT because they feel it is important for consent.

2. No – Use this code when participants indicate that individuals who were between the ages of 12 – 17 years old when agreeing to participate in a biobank should not be contacted at the age of majority to provide consent as an adult. Codes in this category are not exclusive; more than one can apply.

   a. Participant’s Responsibility – Use this code when participants express that re-contact at the age of majority is unnecessary because since the adolescent was aware of participating in the biobank, it is his/her responsibility to contact the biobank if they no longer want to participate.
   
   b. Too difficult – Use this code when participants express that re-contact at the age of majority is unnecessary because it will be too difficult to re-contact every single participant.
   
   c. Consent already given – Use this code when participants express that re-contact at the age of majority is unnecessary because consent was already granted and that consent should be enough.
   
   d. Not enough time has passed – Use this code when participants express that re-contact at the age of majority is unnecessary because very little time has passed since they gave assent so it is unlikely that anything has changed in that time frame.
   
   e. Wouldn’t change mind – Use this code when participants express that re-contact at the age of majority is unnecessary because they would not change their mind about participating.

3. Depends – Use this code when the participant indicates that re-contact at the age of majority for individuals who were between the ages of 12 – 17 when they agreed to participate in the biobank depends on additional factors.

   a. When assent was given – Use this code when participants indicate that re-contact at the age of majority depends on how old the individual was when they provided assent to participate in the biobank.
   
   b. Level of involvement in decision – Use this code when participants indicate that re-contact at the age of majority depends on how much of a role the individual played in the consent/assent process (i.e. how much their parents considered their opinion).
   
   c. Participant’s agreement – Use this code when participants indicate that all individuals participating in a biobank should be asked if they want to be re-contacted when they turn 18 years old and that re-contact depends on how the participant answered this question.

H. What to do with samples – This theme focuses on participants responses to questions regarding what should be done with the samples and health information if the biobank is unable to reach a participant for re-consent once they reach the age of majority.

   1. Do not use them – Use this code when a participant indicates that samples and health information should not be used until the biobank is able to reach the
individual for re-consent as an adult. DO NOT use this code if the participant indicates that samples and health information should be destroyed.

2. Destroy – Use this code when a participant indicates that samples and health information should be destroyed if the biobank is unable to reach the individual for re-consent as an adult.

3. Continue to use them – Use this code when a participant indicates that samples and health information should continue to be used because previous consent and/or assent was already given.

4. Contact parents – Use this code when a participant indicates that if the biobank is unable to reach an individual once they reach the age of majority they should attempt to contact parents.

5. Depends – Use this code when a participant indicates that what should be done with the samples and health information if the biobank is unable to reach a participant for re-consent depends on other factors.
   a. On researchers – Use this code when a participant indicates that what is done with the samples depends on what the researchers think the usefulness of the sample is, what the researchers believe is the right thing to do or if the researchers feel the sample has gotten too old.
   b. Participant’s agreement – Use this code when participants indicate that what is done with the samples depends on what the participant indicated they wanted done with the first agreed to be in the biobank.
   c. Sample – Use this code when a participant indicated that what is done with the sample depends on how useful, rare, or unique the sample is or if the sample is of some use for a specific study.

6. Keep trying/try another way – Use this code when a participant indicated that if the biobank is unable to reach an individual once they reach the age of majority they should just keep trying or they should try reaching them another way (e.g. if you had been trying to reach them by phone you should try reaching them by mail).

I. Use if key destroyed – This theme focuses on participants responses to the question about if it would be alright to continue to use samples and health information for children and adolescents if the key linking their identifying information to the samples/health information was destroyed.

   1. Yes – Use this code when participants indicate that it would be ok to continue to use the samples and health information if the key was destroyed.
      a. Wouldn’t know who it belonged to – Use this code when participants express that using samples once the key was destroyed is ok because no one would know that the samples and health information belonged to them so there is no risk to privacy.
      b. Consent previously given – Use this code when participants express that using samples and health information once the key was destroyed would be ok because consent was previously given.
      c. Know research process – Use this code when participants express that using the samples and health information once the key was destroyed would be ok as long as researchers know what they are doing.
2. 
No- Use this code when participants indicate that it would not be ok to continue to use the samples and health information if the key was destroyed.
   a. Everything or nothing – Use this code when participants express that using the samples and health information if the key was destroyed is not ok because you should either have all of the information (key, samples and health information) or none of the information; it is not ok to only keep some of the information.
   b. No record – Use this code when participants express that using the samples and health information if the key was destroyed is not ok because you would no longer have record of whose samples were whose so participants would not know where their samples have gone.
3. 
Depends – Use this code when participants indicate that using the samples and health information if the key was destroyed depends on additional factors such as how rare the sample is, what they research the sample is being used for is trying to find, etc.

J. Destroy Samples – This theme primarily focuses on participants responses to the question about if the samples and health information should be destroyed if the biobank was unable to get in touch with the individual once they turned 18 years old.
1. 
Yes – Use this code when participants indicate that samples and health information should be destroyed if they are unable to reach an individual once they turn 18 years old.
   a. Right to own consent – Use this code when participants indicate that samples should be destroyed if the biobank is unable to reach an individual once they turn 18 years old because the individual has a right to give their own consent for the use of their samples.
   b. Now an adult - Use this code when participants indicate that samples should be destroyed if the biobank is unable to reach an individual once they turn 18 years old because the individual is now 18 years old and is an adult and is responsible for their own decisions.
   c. Disagree with parents – Use this code when participants indicate that samples should be destroyed if the biobank is unable to reach an individual once they turn 18 years old because they not agree with the decision that their parents made for them.
   d. Trust researcher’s decision – Use this code when participants indicate that samples should be destroyed if the biobank is unable to reach an individual once they turn 18 years old if that is what the researchers feel is the best decision.
2. 
No – Use this code when participants indicate that samples and health information should NOT be destroyed if they are unable to reach an individual once they turn 18 years old.
   a. Consent already given – Use this code when participants indicate that samples and health information should NOT be destroyed if they are unable to reach an individual once they reach 18 years old because consent was previously given and should remain in effect.
   b. May help someone – Use this code when participants indicate that samples and health information should NOT be destroyed if they are unable to
reach an individual once they turn 18 years old because the samples may still help people in the future.

c. Participant holds responsibility – Use this code when participants indicate that samples and health information should NOT be destroyed if they are unable to reach an individual once they turn 18 years old because the participant is responsible for contacting the biobank if they no longer want to participate.

d. May reach participant later – Use this code when participants indicate that samples and health information should NOT be destroyed if they are unable to reach an individual once they turn 18 years old because they may still be able to reach the participant later on down the road.

K. Data Sharing under 12 years old – This theme primarily focuses on participants responses to question about data sharing for individuals who are under the age of 12 years old.

1. Yes – Use this code when participants express that it is ok to share samples and health information for children under the age of 12 years old with researchers at other institutions.

   a. Trust in parents decisions – Use this code when participants indicate that it is ok to share samples for children under the age of 12 years old because they would trust the decision that the parents made for their child.

   b. Help others – Use this code when participants indicate that it is ok to share samples for children under the age of 12 years old because it might help to find treatments or cures for diseases which might help other people.

   c. Consent was given – Use this code when participants indicate that it ok to share samples for children under the age of 12 years old because consent was given to be in the biobank.

   d. Promote scientific research – Use this code when participants indicate that it is ok to share samples for individuals under the age of 12 years old because it could help contribute to scientific research or the advancement of knowledge.

   e. Trust in biobank governance – Use this code when participants indicate that it is ok to share samples for individuals under the age of 12 years old because they trust in the data sharing process or that they trust in the policies and procedures that are put in place within the biobank that govern data sharing (i.e. trust that samples will only be shared with appropriate research personnel).

2. No – Use this code when participants indicate that it is not ok to share samples for children under the age of 12 years old with researchers at other institutions.

   a. Vulnerable population – Use this code when participants indicate that it is not ok to share samples for children under the age of 12 years old because they are too young and vulnerable.

   b. Lack of awareness – Use this code when participants indicate that it is not ok to share samples for children under the age of 12 years old because they may not be aware that their parents had agreed for them to be part of the biobank.
c. May not agree with parents’ decision – Use this code when participants indicate that it is not ok to share samples for children under the age of 12 years old because they may not agree with the decision their parents made.

d. Did not give own consent – Use this code when participants indicate that it is not ok to share samples for children under the age of 12 years old because they did not provide their own consent to participate.

e. Loss of privacy – Use this code when participants indicate that it is not ok to share sample for children under the age of 12 years old because they are concerned with a loss of privacy or are concerned about samples getting into the wrong hands.

f. Unable to get samples back - Use this code when participants indicate that it is not ok to share samples and health information for individuals under the age of 12 years old because it may be difficult to get samples back if participant withdraws consent.

3. Depends – Use this code when participants indicate that data sharing of samples for children under the age of 12 years old depends on the situation.

   a. Participant’s medical history – Use this code when participants indicate that data sharing of samples from individuals under the age of 12 years old depends on if the participant has a medical condition or is a healthy individual.

   b. Rare sample – Use this code when participants indicate that data sharing of samples from individuals under the age of 12 years old depends on if the participants sample is a rare sample and could be useful for research purposes.

   c. Participant’s agreement – Use this code when participants indicate that data sharing of samples from individuals under the age of 12 years old depends on whether or not the participant was asked if their sample could be shared and if they agreed to data sharing.

   d. Specific study – Use this code when participants indicate that data sharing of samples from individuals under the age of 12 years old depends on the specific study that the samples will be shared for.

4. Don’t know – Use this code when participants indicate that they are unsure how they feel about data sharing for children under 12 years.

L. Data sharing 12 – 17 years old – This theme primarily focuses on participants’ response to question about data sharing for individuals between the ages of 12 – 17 years old.

1. Yes – Use this code when participants indicate that it is ok to share samples for individuals between the ages of 12 – 17 years old with researchers at other institutions.

   a. Assent given – Use this code when participants indicate that it is ok to share samples and health information for individuals who are between the age of 12 – 17 years old because they gave assent and she understand what that means.

   b. Help others - Use this code when participants indicate that it is ok to share samples for children between the age of 12 – 17 years old because it might help to find treatments or cures for diseases which might help other people.
c. Promote scientific research – Use this code when participants indicate that it is ok to share samples for individuals between the ages of 12 – 17 years old because it could help contribute to scientific research or the advancement of knowledge.

d. Trust in biobank governance – Use this code when participants indicate that it is ok to share samples for individuals between the ages of 12 – 17 years old because they trust in the data sharing process or that they trust in the policies and procedures that are put in place within the biobank that govern data sharing (i.e. trust that samples will only be shared with appropriate research personnel).

2. No- Use this code when participants indicate that it is NOT ok to share samples for individuals between the ages of 12 – 17 years old with researchers at other institutions.

   a. Loss of privacy – Use this code when participants indicate that it is not ok to share samples and health information for individuals between the ages of 12 – 17 years old because of concerns over loss of privacy.
   
   b. Unable to get samples back – Use this code when participants indicate that it is not ok to share samples and health information for individuals between the ages of 12 – 17 years old because it may be difficult to get samples back if participant withdraws consent.
   
   c. Not an adult yet – Use this code when participants indicate that it is not ok to share samples and health information for individuals between the ages of 12 - 17 years old because they are not an adult yet and may not fully understand the implications of being in a biobank.

3. Depends – Use this code when participants indicate that data sharing of samples for children between 12 – 17 years old depends on the situation.

   a. Participant’s medical history – Use this code when participants indicate that data sharing of samples from individuals between 12 - 17 years old depends on if the participant has a medical condition or is a healthy individual.
   
   b. Rare sample – Use this code when participants indicate that data sharing of samples from individuals between 12 - 17 years old depends on if the participants sample is a rare sample and could be useful for research purposes.
   
   c. Participant’s agreement – Use this code when participants indicate that data sharing of samples from individuals between 12 - 17 years old depends on whether or not the participant was asked if their sample could be shared and if they agreed to data sharing.
   
   d. Specific study - Use this code when participants indicate that data sharing of samples from individuals between the ages of 12 to 17 years old depends on the specific study that the samples will be shared for.

4. Don’t know – Use this code when participants indicate that they are unsure how they feel about data sharing for children between 12 - 17 years old.

M. Misunderstanding of biobanks – This theme primarily focuses on participant’s responses that indicate that they may not have the correct understanding of what a biobank is.
1. Blood bank – Use this code when participants indicate at any point during the interview that their understanding of a biobank is that it is similar to a blood bank where individuals may be able to receive transfusions from their samples that are stored in the biobank or may receive some sort of tissue transplant from their samples that are stored in a biobank.

2. Patient Care – Use this code when participants indicate at any point during the interview that their understanding of a biobank is that the samples stored are used for clinical patient care as opposed to being used for research.

3. Fundraising – Use this code when participants indicate at any point during the interview that their understanding of a biobank is that it is a way to raise money for research.

N. Duration of re-contact efforts – This theme primarily focuses on participants responses to how long the biobank should try to re-contact participants once they reach the age of majority.

   1. Length of time – Use this code when participants indicate that re-contact should be attempted for a certain length of time (e.g. weeks, months, years)

   2. Number of attempts – Use this code when participants indicate that re-contact should be attempted a certain number of times as opposed to over certain duration of time.

O. Waste/Efficiency – This theme primarily focuses on participants responses at any point during the interview that indicates that the efficiency of biobanks/biobanking or waste of resources somehow contributes to their opinions on biobanking.

P. Relation to school curriculum – This theme primarily focuses on participants responses at any point during the interview where they relate their views about biobanks to what they are learning/have learned in school.