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### Title

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### Permalink

<https://escholarship.org/uc/item/6n464543>

### Journal

Journal of the American Medical Informatics Association, 27(12)

### ISSN

1067-5027

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### Publication Date

2020-12-09

### DOI

10.1093/jamia/ocaa235

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Peer reviewed

## Review

# A systematic literature review of Native American and Pacific Islanders' perspectives on health data privacy in the United States

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Received 14 July 2020; Editorial Decision 29 August 2020; Accepted 14 September 2020

## ABSTRACT

**Background:** Privacy-related concerns can prevent equitable participation in health research by US Indigenous communities. However, studies focused on these communities' views regarding health data privacy, including systematic reviews, are lacking.

**Methods:** We conducted a systematic literature review analyzing empirical, US-based studies involving American Indian/Alaska Native (AI/AN) and Native Hawaiian or other Pacific Islander (NHPI) perspectives on health data privacy, which we define as the practice of maintaining the security and confidentiality of an individual's personal health records and/or biological samples (including data derived from biological specimens, such as personal genetic information), as well as the secure and approved use of those data.

**Results:** Twenty-one studies involving 3234 AI/AN and NHPI participants were eligible for review. The results of this review suggest that concerns about the privacy of health data are both prevalent and complex in AI/AN and NHPI communities. Many respondents raised concerns about the potential for misuse of their health data, including discrimination or stigma, confidentiality breaches, and undesirable or unknown uses of biological specimens.

**Conclusions:** Participants cited a variety of individual and community-level concerns about the privacy of their health data, and indicated that these deter their willingness to participate in health research. Future investigations should explore in more depth which health data privacy concerns are most salient to specific AI/AN and NHPI communities, and identify the practices that will make the collection and use of health data more trustworthy and transparent for participants.

**Policy Points:**

- While many American Indian/Alaska Native (AI/AN) and Native Hawaiian or other Pacific Islander (NHPI) individuals are supportive of research that may benefit the health of their communities, they are frequently deterred from participating due to concerns about the privacy of their health data.
- Respondents expressed concerns about how their biosamples and health data would be used in research and believed that current processes of consent were insufficient.
- Future research and policy development pertaining to AI/AN and NHPI data privacy should focus on *collective* privacy risks (ie, risks incurred to communities rather than just individuals) and strategies to mitigate those risks.

**Key words:** privacy, health information, personal genetic information, research ethics, Indigenous populations

## INTRODUCTION

Issues related to privacy frequently emerge as a barrier to equitable participation in health research and thus to the applicability of its results for American Indian/Alaska Native (AI/AN) and Native Hawaiian and Pacific Islander (NHPI) groups in the United States (US). There is a robust literature on various aspects of health-related privacy such as data sharing, donation and handling of biospecimens, consent, and confidentiality, and how concerns about these factors influence underrepresented groups' willingness to participate in health research (eg, clinical trials, cancer research, genetic and genomic research). However, studies focused on the specific concerns of AI/AN and NHPI communities, including systematic reviews, are lacking.

Due to historical abuses of Indigenous communities in research such as the Diabetes Project with the Havasupai Tribe and the Human Genome Diversity Project (HGDP), some AI/AN and NHPI communities express justifiable skepticism and concern about participating in research.<sup>1,2</sup> In both cases, mistreatment of Indigenous communities resulted from issues related to the attainment, management, or use of Indigenous biospecimens or data, as well as the interpretation and representation of findings related to those data. We briefly outline these studies and reflect on the harms they have inflicted on Indigenous communities including stigmatization, lack of benefit, and violation of privacy rights and cultural values.

A legal dispute between the Havasupai Tribe in Arizona and Arizona State University (ASU) demonstrates an instance of research misconduct involving issues related to informed consent. In 1989, Havasupai tribal leaders reached out to an ASU anthropologist and trusted contact of the tribe, Dr. John Martin, in the hopes of addressing the high rates of diabetes in their community. Martin enlisted genetic researcher Dr. Therese Markow to collect DNA samples and study whether a genetic link to diabetes existed in the community.<sup>2</sup> ASU researchers collected blood from approximately 400 Havasupai tribal members in connection to the Diabetes Project.<sup>1</sup> This was the first time the tribe participated in research requiring the collection of blood, which they regard with spiritual and cultural significance.<sup>3</sup> Later, without approval from the tribe, Markow and other researchers used the DNA samples for unrelated studies on culturally taboo topics including schizophrenia, inbreeding, and migration. This came to light in 2003 when Carletta Tilousi, a participant in the study, attended a doctoral defense sharing the results of population migration studies using data derived from the Havasupai blood samples. The Havasupai Tribe sued ASU for misuse of their blood samples and lack of informed consent. In

2010, the Havasupai Tribe and ASU Board of Regents reached a settlement agreement which included financial compensation to tribal members, provision of support for education and economic development, and, most importantly to the community, the return of the remaining 151 blood samples.<sup>3</sup>

The HGDP was a worldwide DNA mapping study aimed at understanding human origins and migration. At the outset of the project in the 1990s, an international team of genetic and anthropological researchers sought to collect DNA samples from "isolated" and "vanishing" Indigenous communities whose genomes they described as containing "information needed to reconstruct our evolutionary history."<sup>4</sup> The HGDP generated significant controversy among Indigenous leaders, organizations, and communities around the globe, who raised concerns over the ownership of biological samples, as well as data, and acknowledged the potential for exploitation of Indigenous communities via the commercialization or patenting of their genetic material. The project was also criticized for its extractive nature as researchers would arrive to Indigenous communities with the sole purpose of collecting samples, then leave with no further communication or concern for the welfare of the community. Debra Harry, Executive Director of the Indigenous Peoples' Council on Biocolonialism (an organization developed in HGDP's wake) cogently questioned the HGDP's dehumanizing treatment of Indigenous Peoples as objects of research: "Why the tremendous interest in saving the genes of Indigenous people and not the people themselves?"<sup>5</sup>

Despite negative impacts of research misconduct and privacy violations on Indigenous communities around the globe, Indigenous Peoples continue to show interest and participate in health research. In the US, at least 28 AI/AN tribes or tribal organizations have participated in research through the Native American Research Centers for Health, an initiative launched in 2000 between the National Institutes of Health (NIH) and the Indian Health Services (IHS),<sup>6</sup> and 12 tribal communities participate in health research through Tribal Epidemiology Centers, which involves partnership between IHS, a variety of state or federal agencies, and academic institutions.<sup>7</sup> AI/AN people have also developed tribal research infrastructure to ensure benefits and protections for AI/AN individuals and communities participating in research. Entities including tribal nations, tribal colleges, tribal institutional review boards (IRBs), and the IHS contribute to a diverse set of mechanisms providing oversight of research involving AI/AN individuals and communities.<sup>8</sup>

Still, the impact of research violations on Indigenous Peoples is visible in their general underrepresentation in US health research.

For AI/AN and NHPI individuals and communities, decisions about whether or not to participate in research are often shaped by concerns that arise from past abuses, often related to privacy violations as well as the availability of adequate research protections.<sup>2,9,10</sup> The above examples demonstrate the necessity of research protections not only for biospecimens but for health data, including (but not limited to) those which are derived from biospecimens.

Thus, in order to pursue more equitable representation of Indigenous Peoples in health research, it is important to understand key privacy issues that may arise in the conduct of that research. To specifically understand what is known about US Indigenous perspectives on the topic of health data privacy, and to inform research practice for those investigators working with these communities and their health data, we conducted a systematic review of the literature on AI/AN and NHPI perspectives on privacy as it relates to health research.

While we refer to AI/AN and NHPI groups collectively as “US Indigenous,” we emphasize that the heterogeneity of these populations is important to note. There are 574 federally recognized tribes in the US, approximately 60 state recognized tribes,<sup>11</sup> hundreds more that are unrecognized by the US or state governments, and many other diverse NHPI communities. We also separate AI/AN from NHPI to acknowledge the distinctness of Indigenous communities whose ancestral lands are located in the mainland US from those who are Indigenous to Oceania (and reside in the US). Moreover, as a result of their distinct histories of (and resistances to) colonization by the US, there are notable differences in the infrastructures that provide health care and other resources to AI/AN and NHPI communities (for instance, IHS serves AI/AN people but not NHPI people).

Given that data-sharing preferences and privacy perspectives vary across different AI/AN and NHPI communities, and due to the heterogeneity of methodological approaches in the included studies, we analyzed results using qualitative synthesis rather than meta-analysis. Our findings should thus be contextualized as representing the range of AI/AN and NHPI communities’ perspectives on health data privacy in the literature rather than fully representing all Indigenous communities in the US.

## MATERIALS AND METHODS

### Definitions

Others have written about the challenges of defining a term as broad and multifaceted as *privacy*, which is often conflated or used interchangeably with related concepts such as confidentiality and anonymity.<sup>12</sup> We were interested in studies about AI/AN and NHPI perspectives on *health data privacy*, which we understand as the practice of maintaining the security and confidentiality of an individual’s personal health records and/or biological samples (including genetic or other data derived from biological specimens), as well as the secure and approved uses of those data.

### Literature search strategy

This review was conducted and reported using the PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) protocol for systematic reviews.<sup>13</sup> We conducted a systematic search of the literature on AI/AN and NHPI perspectives on health data privacy using the following databases: PubMed, Web of Science, PsycInfo, CINAHL, Bibliography of Native North Americans, and Sociological Abstracts. Our search strategies (Supplementary S1 Ta-

ble) were adjusted according to each database, using keywords and Medical Subject Headings related to health data privacy (eg, “privacy,” “data sharing,” “confidentiality,” “biobanking”), and restricting results to English. Our searches were conducted between November and December 2018 and then updated in February 2020. We did not restrict searches based on year of publication.

Initially, our search retrieved 1664 publications. After removing duplicates, 1457 results remained. We began manual screening by eliminating texts that were not peer-reviewed (eg, dissertations, books, book chapters). We made note of excluded dissertations, books, and book chapters that seemed relevant to AI/AN and NHPI privacy views, in order to review the bibliography for additional, eligible studies. We excluded texts about populations that were clearly not located in the US, based on the title.

### Article selection

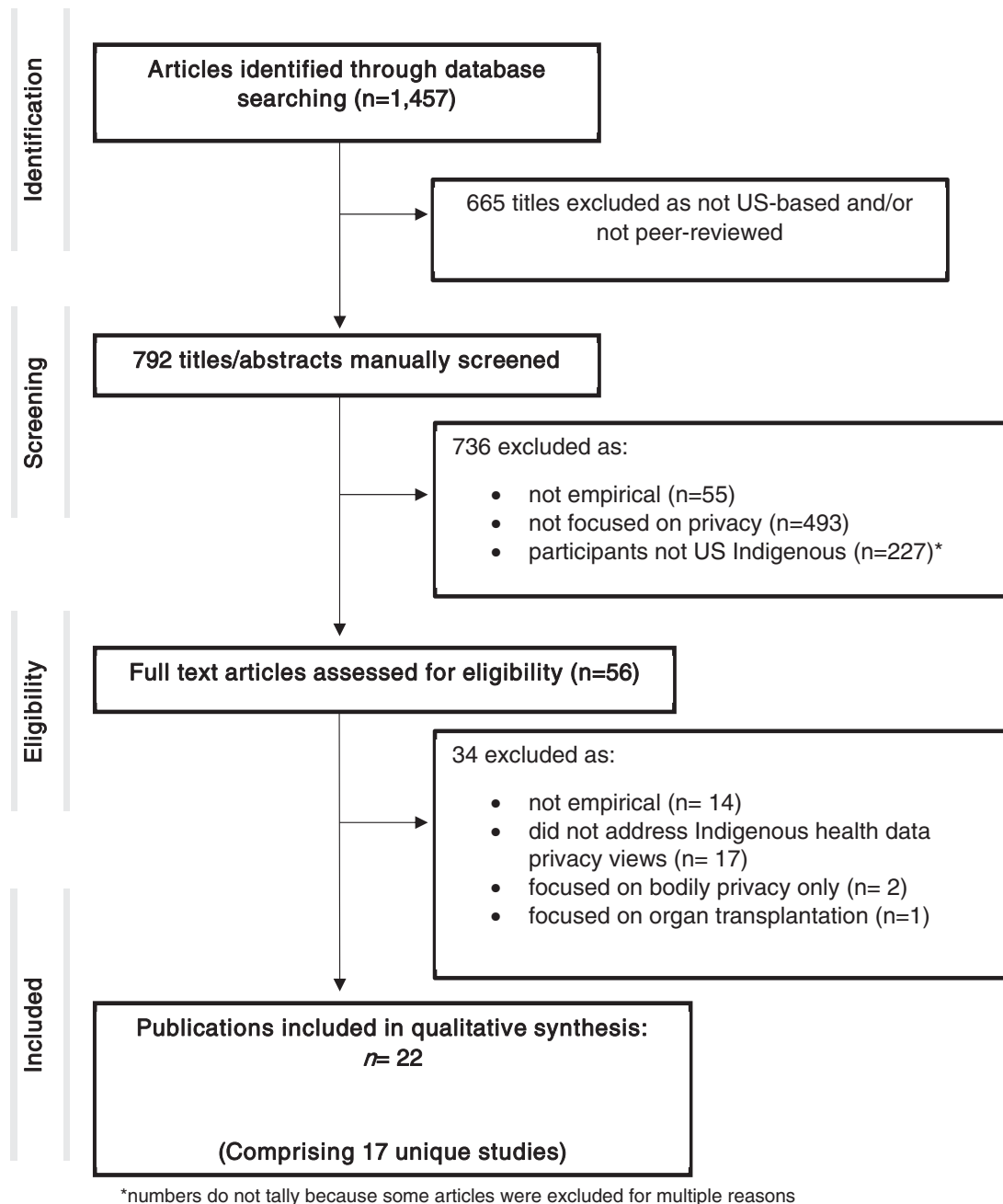
After the first phase of screening, 792 texts remained. Two reviewers (RT and CT) manually screened these titles and abstracts, coding for inclusion or exclusion based on the following criteria: 1) US-based population; 2) Peer-reviewed; 3) Empirical (qualitative, quantitative, or mixed-methods studies); and 4) Included discussion relevant to health privacy beliefs of AI/AN or NHPI communities. Given our interest in empirical studies, we excluded commentaries and reviews. For inclusion criteria 4, we accepted studies that focused directly on health privacy (including related topics such as confidentiality, data sharing, informed consent, personal health data), as well as those focused on a different, health-related topic, in which privacy emerged as a theme in the results or discussion sections. Disagreements between reviewers were resolved by a third reviewer (CB) to reach consensus.

### Data extraction and analysis

Of the 792 titles and abstracts reviewed, we excluded 736 texts that did not meet our eligibility criteria, resulting in 56 articles for full-text review. We assessed the full-text of the remaining 56 articles and excluded an additional 34 articles because they (i) were not empirical ( $n=12$ ), (ii) did not discuss Indigenous views of privacy ( $n=19$ ), (iii) focused exclusively on bodily privacy in the provision of clinical procedures (eg, administration of pap tests or HPV tests) ( $n=3$ ), or (iv) focused on organ donation and transplantation ( $n=1$ ). When we updated our searches in February 2020, 4 new articles were identified as eligible for inclusion. In all, 26 publications comprising 21 unique studies satisfied our eligibility criteria (Figure 1).

Two reviewers (RT, JC) performed independent quality assessment of studies using questions adapted from published criteria on the quality assessment of interview, focus group, and survey studies.<sup>14,15</sup> Discrepancies were resolved in conversation with a third reviewer (CB). Scoring was based on a total of 12 criteria distributed across the following domains: (i) description of aims and objectives, (ii) description of methods, (iii) participant selection, (iv) data collection, (v) data analysis, (vi) reporting, and (vii) engagement. The questions used for quality assessment are listed in Supplementary S2 Table. Articles scoring 10–12 were rated “good;” articles scoring 7–9 were rated “fair” and those scoring 6 or lower were rated “poor.” A detailed breakdown of quality assessment for each study is presented in Supplementary S3 Table.

For each study, Supplementary S4 Table describes the study population, methods, quality assessment rating, urban/rural residency, and key findings related to privacy. While reviewing the full-text



**Figure 1.** PRISMA Flowchart of article searching and exclusion.

articles, we derived a list of major themes reflecting the specific aspects of privacy raised by participants in the studies. The discussion section is organized along these themes.

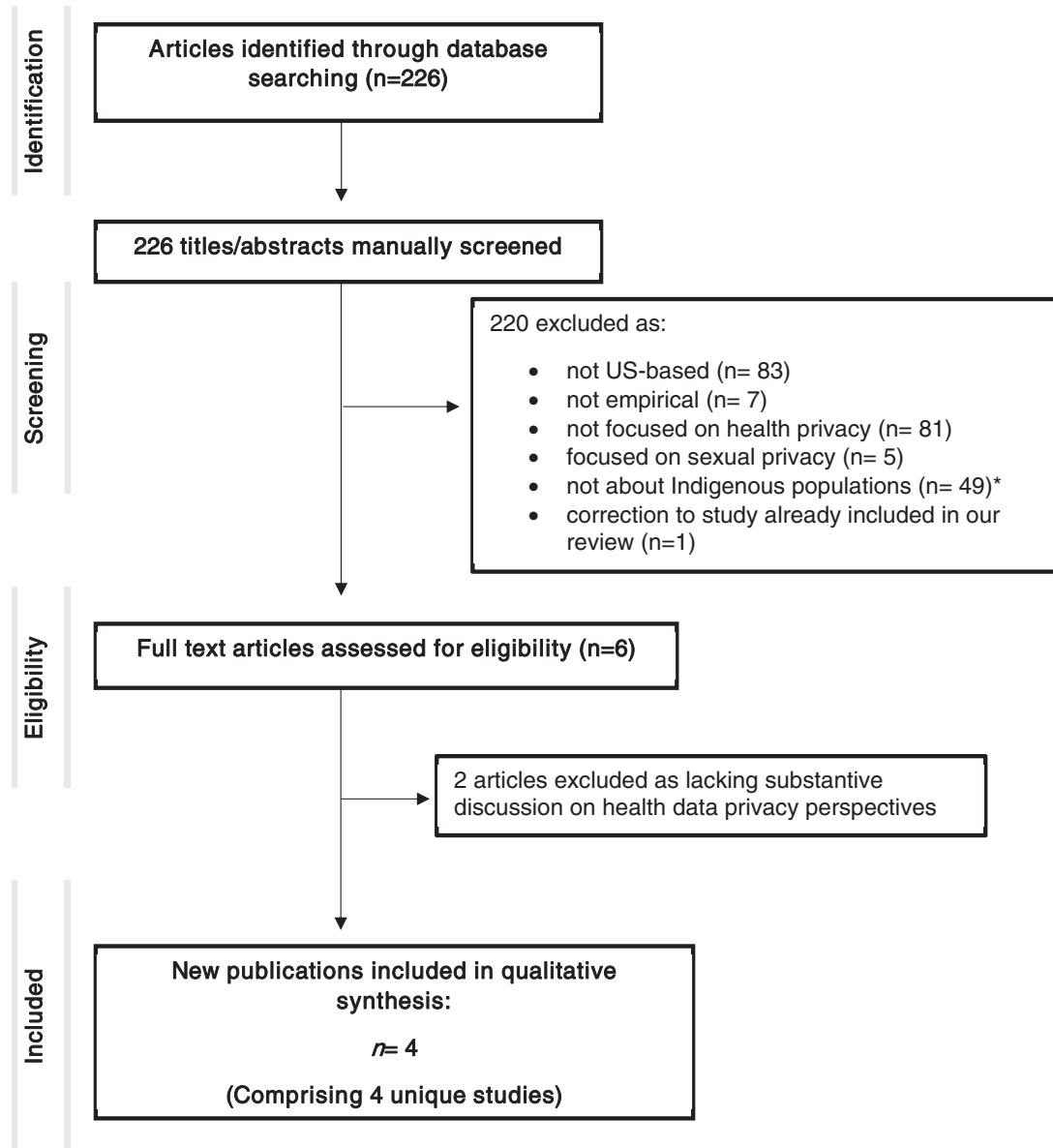
## RESULTS

### Overview

A total of 26 articles comprising 21 unique studies published between 1997 and 2019 were eligible for this review. These 21 studies included interviews (n=4),<sup>16–19</sup> surveys (n=4),<sup>20–23</sup> focus groups (n=9),<sup>24–32</sup> and mixed methods (n=4).<sup>33–36</sup> Two studies were of poor quality, 10 were of fair quality and 14 were of good quality (Supplementary S3 Table).

### Participant demographics

Studies included a total of 3609 participants, of which 3234 identified as AI/AN or NHPI individuals. Non-AI/AN or NHPI participants in these studies included Hispanic (n=123), African American (n=46), Filipino (n=27), Caucasian (n=46), and “other” or individuals who did not disclose their race/ethnicity (n=134). (Numbers do not tally because 1 participant self-identified as both Hispanic and American Indian [Ridgeway, 2019]). We report findings regarding the AI/AN and NHPI participants only. Of the 21 studies, 4 involved NHPI populations and 17 involved AI and/or AN populations. In an effort to protect the identity of study participants, many studies provided limited demographic information (eg, gender, age, education, income), and the



\*numbers do not tally because some articles were excluded for multiple reasons

Figure 1. continued

majority did not disclose the names of specific tribes involved in the studies. For the 19 studies that reported on gender, 15 featured a majority of female participants,<sup>10,19–24,28–32,34,35,37</sup> 2 were nearly equally distributed with a slight prevalence toward females (16 females, 15 males; 29 females, 24 males),<sup>18,25</sup> and 1 was near-equal with a slight preference toward males (exact numbers not reported).<sup>16</sup> The vast majority of studies did not distinguish between sex and gender identity. One study offered a category for Two-Spirit/LGBTQ participants.<sup>19</sup> Education was reported for 11 studies<sup>19–22,26,29,31,32,35,37,38</sup> and socioeconomic status was reported for 4 studies.<sup>21,29,35,38</sup> Five studies were conducted exclusively in urban settings,<sup>16,20,28,33,37</sup> 3 were conducted exclusively in rural settings,<sup>25,31,38</sup> and 9 were conducted in a combination of urban and rural settings.<sup>18,21–24,26,27,29,30</sup> Three studies did not specify whether the setting was rural or urban,<sup>19,32,35</sup> and 1 study did not disclose any information about setting.<sup>17</sup>

### Issues explored in the studies

As previously mentioned, some studies undertook a direct investigation of AI/AN or NHPI views on health data privacy, while others focused on a broader topic (eg, barriers to clinical trial participation) and privacy emerged as a key theme or finding. Thus, studies generally fell into 2 broad categories: (i) AI/AN or NHPI views on privacy of biospecimens and (ii) privacy-related barriers to AI/AN or NHPI participation in health research. Given that studies focused on biospecimen privacy also address AI/AN or NHPI reticence to participate in health research, there is some overlap in the discussion across these subsets of the literature. Within these categories, investigators explored a wide range of topics related to the privacy of health data. After reading the 26 full-text articles, reviewers developed the following set of thematic categories based on the topics raised by participants in studies: (i) willingness to participate in health research, (ii) concerns about the potential for discrimination

KEY FINDINGS	SUMMARY
<b>1. Respondents value research that benefits their community.</b>	Many AI/AN and NHPI respondents were supportive of research that may benefit the health of their communities and future generations.
<b>2. Individual-level and collective-level privacy concerns deter AI/AN and NHPI participation in health research.</b>	In addition to individual-level privacy concerns (e.g., loss of access to insurance or tribal resources, misuse of an individual's biological specimen), respondents expressed concerns that participating in health research may harm their collective community (e.g., stigmatization of AI/AN and NHPI communities, dismissal of tribal creation stories, diversion of funds away from AI/AN or NHPI communities).
<b>3. Extant consent processes are inaccessible and insufficient.</b>	Respondents felt that current informed consent materials are written in inaccessible language and lack the appropriate level of detail regarding research goals and processes.
<b>4. Research led by an AI/AN or NHPI investigator may encourage participation.</b>	Some respondents reported an increased willingness to participate in research that is conducted by an AI/AN or NHPI investigator.

Figure 2. Summary of key findings.

based on health data, (iii) concerns about informed consent, and (iv) concerns about breaches of confidentiality. Figure 2 summarizes key findings.

### Willingness to participate in health research

Several studies assessed respondents' willingness to participate in health research involving the collection of personal health data and/or biospecimens. The most common factor increasing willingness was the potential that research may yield health benefits for AI/AN or NHPI communities. For instance, investigators across 3 studies found that AI/AN and NHPI participants showed general support for genetic testing and research involving biospecimens if health benefits can be demonstrated. In an interview study including 150 AI participants, respondents were supportive of genetic screening (ie, for disease susceptibility) if it could potentially improve the health of their communities.<sup>17</sup> A survey study of 1066 students at 3 tribal colleges (representing 3 tribes) assessed AI participants' willingness to participate in 4 health research scenarios presented in vignettes: a focus group study about health, an exploratory genetic study, a behavior intervention, and a clinical drug trial. Investigators found that respondents were significantly more willing to participate in each type of research if they believed benefits (such as new treatments or services) might emerge from the research.<sup>38</sup> A mixed-methods interview and survey study of 60 Pacific Islanders found that 92% of respondents reported that they "understand the benefits of [biospecimen] research," and many indicated they were willing to provide biospecimens (described as blood, skin, hair, nails, or urine) for research that would benefit their community.<sup>36,37</sup>

In a study about Native Hawaiian views on biobanking research, multiple respondents noted the potential for medical research to yield advancements in the prevention, diagnosis, and treatment of disease.<sup>29</sup> Moreover, at least 1 respondent in each of the 10 focus groups in this study connected participation in health research to Native Hawaiian values of helping others or contributing to the "common good." Native Hawaiians in another focus group study were more willing to participate in clinical studies if they perceived

it would benefit their family and/or their broader community.<sup>24</sup> Similarly, a study of AN participants' perceptions of biobanking research found that the vast majority of participants weighed the risks and benefits of biobanking research based on the extent to which participation could benefit future generations,<sup>26</sup> and AI participants in a mixed-methods focus group and survey study rated the potential to help children as the most positive factor of biobanking research.<sup>35</sup>

Many participants' willingness to participate in health research varied with the type of institution conducting the research. The survey study of 1066 AI students at 3 tribal colleges found that the type of institution conducting research significantly impacted respondents' willingness to participate in all 4 types of health research.<sup>38</sup> In particular, investigators found that studies conducted by tribal colleges or universities increased willingness to participate for the vast majority of respondents. Studies conducted by national organizations (eg, the American Diabetes Association, or American Cancer Society) had similar positive effects on likelihood of participation, while studies conducted by the federal government decreased willingness to participate across all types of studies in all but 1 scenario (responses to drug vignette survey at 1 of the 3 colleges). In another survey study of 420 AI/AN patients and staff at an urban multiracial Indian health care facility, investigators found that willingness to participate in all 3 types of health research included in their survey (a behavioral intervention trial, a genetic association study, and a pharmacotherapy trial) decreased significantly if the study was conducted by the federal government.<sup>20</sup>

For many participants, willingness to provide health data for research increased if studies were led by other AI/AN or NHPI community members. In a focus group study exploring factors related to underrepresentation in genomics research, Native American respondents reported a stronger preference than African American respondents for having shared racial or ethnic heritage with the researchers or individuals recruiting them.<sup>27</sup> In a survey study of 112 AI/AN participants over the age of 40, 69% of respondents said they would probably or definitely participate in a hypothetical cancer trial if the lead researcher was also AI/AN.<sup>22</sup> Investigators did



not include a survey item for “if research was not AI/AN,” but did have one for “if a doctor you didn’t know referred you to the study.” In response to this item, only 36% of respondents said they would probably or definitely participate in the hypothetical cancer trial.

When a similar survey was conducted with 489 AI/AN college students, investigators found that 63% of students under the age of 40 and 73% of students age 40 or older would probably or definitely participate in research if it was conducted by an AI/AN investigator.<sup>23</sup> There was no item assessing willingness to participate if research was not conducted by an AI/AN investigator. In another study, Hawaiian respondents believed that Native Hawaiian researchers would be more understanding of Hawaiian cultural values, more responsible for the accessible dissemination of findings back to communities, and more accountable to translating findings into practice than non-Hawaiian researchers.<sup>29</sup>

Another factor that increased willingness to share health data was the establishment of reciprocal relationships between communities and researchers, namely through the adoption of participatory practices that allow for ongoing communication and opportunities for community input to shape the research.<sup>20,22,23,27,38</sup> Notably, in 19 of the studies we reviewed, investigators used community-engaged approaches in the design and/or conduct of their research. This included general partnership with community partners or tribal councils,<sup>16,18,24,28,29,32</sup> consultation with community partners in the development or iterative revision of materials (eg, surveys, focus group guides, or interview guides),<sup>22,23,28,29,39</sup> reinterpretation of data collected in the study,<sup>18,30</sup> or dissemination of an accessible report of study findings to community partners and/or study participants.<sup>24</sup> Some investigators committed to more thorough community engagement by using all of these strategies, partnering with communities as full decision-making stakeholders and co-designers in all stages of the research (eg, community-based participatory research).<sup>26,27,37</sup>

### Potential for discrimination based on health data

In response to investigators’ questions about perceived risks of providing personal information for health research, participants discussed the possible uses of their information for discriminatory purposes, against them individually and collectively. Respondents often expressed concerns that their information may be interpreted in ways that could prevent their access to certain resources or economic opportunities, and/or reinforce stigmas about AI/AN or NHPI communities in general.

Multiple participants in an interview study about DNA biobanking were concerned that insurance companies may discriminate against them on the basis of race or disease prevalence in their community, resulting in higher insurance rates or even outright denial of insurance.<sup>16</sup> These concerns were also reflected in a focus group study involving 73 AIs, in which participants felt that health research may result in higher insurance rates, denial of care, or job loss.<sup>30</sup> Participants in a study about AN perspectives on pharmacogenetics were concerned that the clinical use of pharmacogenetics may also lead to reduced health care access for ANs, through the diversion of funds from other health care needs.<sup>28</sup>

AN respondents in another focus group study commented on the potential harmful impacts of findings on participants’ claims to Indigenous identity, for instance in relation to the contentious issue of blood quantum to meet tribal enrollment criteria (eg, when tribes require a specific proportion or quantum of tribal or AI/AN blood,

such as one-quarter for tribal membership or citizenship), which may in turn result in the loss of access to tribal resources.<sup>26</sup> Respondents in this study were also concerned about the potential for their genetic information to be interpreted in ways that dismiss tribal creation stories, while AI participants in another focus group study discussed potential tensions between genetic research on ancestry and migration and cultural or spiritual beliefs.<sup>32</sup>

In another focus group study, AN participants feared the misuse of their genetic information from clinical practice or research, worrying that it may result in stigma, for instance through the association of certain medical conditions with their communities.<sup>28</sup> Finally, participants in the focus group study with 73 AIs discussed the difficulty of maintaining privacy in small, rural communities, and raised concerns about how research results may lead to the stigmatization of particular individuals and impact relations within the community.

### Concerns about informed consent

The most widely explored topic across all studies reviewed was participants’ privacy views in relation to informed consent processes in health research. Three studies focused on consent in health research in general<sup>18,24,30</sup> and 10 studies discussed consent in the context of research involving biological specimens.<sup>16,21,25,26,28,29,32,33,35,37</sup>

In the 3 studies that explored informed consent in the broad context of biomedical or health research, AI/AN and NHPI respondents alike raised concerns about extant informed consent processes, and worried that researchers do not exercise full transparency about research to participants.<sup>18,24,30</sup> For instance, AIs in 1 focus group study felt that consent processes do not guarantee confidentiality or complete understanding,<sup>30</sup> and Native Hawaiian respondents in another focus group study stated that they were concerned or did not know about the process of informed consent.<sup>24</sup> Respondents in the latter study frequently described research as “secretive” and felt that research participants are generally not given adequate information to make informed decisions about participation. Similarly, in an interview study with AIs, some respondents cited past practices in research and health care as shaping their concerns about informed consent, for instance the Indian Health Services’ (IHS) forced sterilizations of Native women in the 1960s and 70s.<sup>18</sup> These respondents were concerned that researchers may conduct studies without obtaining proper informed consent, and some respondents worried that they or their family members might have already been included in IHS research without consent.

Ten studies addressed informed consent in the context of research involving biological specimens, including 3 focused on NHPI participants and 7 on AI/AN participants. In general, AI/AN and NHPI participants in these studies identified significant issues with current informed consent processes and shared a range of preferences regarding the use of biospecimen.

The studies featuring NHPI participants pointed to significant issues with existing informed consent processes and underscored the need for opportunities to re-consent to the use of biospecimens in secondary studies. One survey study found that Native Hawaiians were more likely than Whites in a national sample to want an informed consent process for the use of their biospecimens.<sup>39</sup> In particular, 78% of 429 Native Hawaiians said they would want to provide consent for the reuse of identified specimens, and 35% wanted to provide consent for the reuse of anonymized specimens. Comparatively, in the national sample of 456 Whites, 29% preferred to consent for



the reuse of identified specimens, and 11% for the reuse of anonymized specimens.

A focus group study on Native Hawaiians' views on biospecimen-based research also highlighted preferences for re-consent, with investigators reporting that the majority of the 92 respondents discussed the need to be re-consented each time their tissue was requested for use.<sup>29</sup> Finally, a mixed-method interview and survey study including a broader sample of Pacific Islanders (Native Hawaiians, Samoans, Chamorros, Tongans, Marshallese, 1 Palauan, and 1 Māori) also underscored the need for adequate informed consent processes in biospecimen research, as some respondents feared their samples would be sold for profit or used in unethical ways.<sup>37</sup>

AI/AN respondents also commonly voiced concerns about informed consent in research involving biospecimens, and pointed to specific ways these processes may be improved.<sup>16,25,26,33</sup> For instance, AI/AN respondents in 2 studies cited legal and medical jargon as a barrier to true informed consent, and called for more accessible language in consent forms.<sup>26,33</sup> In a focus group study about the acceptability of pharmacogenetic research in AN communities, respondents under the age of 40 believed informed consent processes must be culturally competent as well as account for the communicative differences across communities and generations.<sup>28</sup> AI respondents in another focus group study recommended that tribal leaders help community members make informed decisions about research participation by distributing relevant information to local tribal offices, community centers, and stores prior to recruitment.<sup>25</sup>

Additionally, investigators in a focus group study with 24 AI participants suggested that beyond using accessible or plain language for informed consent, researchers might consider tailoring consent documents to reflect the language used within a specific community when discussing genetics or biological samples.<sup>32</sup> For instance, since AI participants in their study talked about biosamples (and the genetic information derived from them) in terms of ancestral "bloodline," the authors recommended using the same terminology in consent forms to help participants connect with otherwise unfamiliar topics like biobanking and genetic research.

AI/AN participants varied considerably in their preferences regarding biosample use. In 1 focus group study, participants reported more willingness to provide biosamples for medical diagnosis or treatment rather than for research, given that in the former, diagnostic samples are collected for a specific purpose, discarded after analysis, and the results are returned in a timely manner with direct health-related benefit to the individual.<sup>25</sup> Alternatively, participants in other studies considered providing biospecimens for research as long as there were more ongoing processes of communication regarding their samples and data derived from them. For instance, in a focus group study about providing biospecimens for cancer research, AN participants expressed a desire for more frequent and detailed communication about who would be accessing their data; the purposes for which it would be accessed; the duration for which it would be used; and what would happen to their biosample upon completion of the research study.<sup>31</sup>

Similarly, in a study involving 16 in-depth interviews with AI individuals, investigators reported that many participants wanted more regular connections with their biospecimens, being continuously made aware of their sample's location, as well as what has been done to it and any scientific discoveries made from it.<sup>16</sup> In this study, investigators also reported that while some participants expressed hesitation in providing biological samples in connection to a belief that doing so would interfere with "body wholeness," the

most common barrier to giving away a DNA sample stemmed from a distrust of governmental or private institutions for fear that their sample may be commodified.<sup>16</sup>

Another interview study explored the notion of body wholeness in more depth. In this study involving 53 AIs, 65% of respondents who self-identified as more "traditional" (eg, adhering to tribal cultural values and practices) preferred that biospecimens be returned to the individual at the end of a research study, and 50% felt that a biospecimen belongs to the individual who provided it.<sup>40</sup> By comparison, 30% of those respondents who self-identified as "nontraditional" felt that biospecimens should be returned, and 26% agreed that biospecimens belong to the individual from whom it came. This study also found that 35% of respondents who identified as traditional believed that biospecimens should not be used in research after the research participant's death, while 7% of nontraditional people shared this belief. Similarly, some AN participants in a focus group study suggested that consent documents provide an option for a "destroy by" date, or the option to have the sample destroyed after the participant's death.<sup>26</sup>

### Concerns about breaches of confidentiality

Finally, confidentiality was an infrequent but salient topic across the included studies. While confidentiality and privacy are often used interchangeably in everyday conversation and are generally not defined or operationalized in the articles included in this review, they do hold distinctly different meanings from a legal standpoint. Confidentiality refers to personal information shared with another party (eg, attorney, physician, therapist, or other individual) that generally cannot be divulged to additional parties without the express consent of the client.<sup>41</sup> Though several studies asked participants directly about risks related to "confidentiality" or "breaches of confidentiality," just 1 survey study offered some clarification on the term, expanding on the risk of broken confidentiality as: "your personal experiences, thoughts, feelings, opinions or health problems" could become "known to other people."<sup>22</sup> Though not as deeply or systematically explored as other topics, findings related to the issue of confidentiality in the included studies elucidate important considerations for future work. In particular, 4 of the studies that directly addressed confidentiality found that respondents were less likely to participate in health research if there was a risk that confidentiality may be broken.<sup>20,22,23,38</sup>

Some studies directly addressed confidentiality but did not necessarily measure the influence of confidentiality perspectives on participation in research. In a survey conducted with 37 females across AI, Hispanic, and White/non-Hispanic groups, respondents were asked to rate the degree to which they "trust medical researchers to keep [their] samples and medical information confidential and private."<sup>35</sup> On average, AI respondents reported lower trust of medical research than the Hispanic and White/non-Hispanic respondents in the study. An interview study with 37 AI/AN/NHPI clinicians, researchers, policy makers, tribal leaders, and tribal research review board members found that many respondents felt that privacy and confidentiality issues in research were serious enough to warrant closed or restricted access to Indigenous genomic data.<sup>19</sup> Respondents cited risks of data reidentification, particularly in small communities, that could compromise the confidentiality of tribes, communities, or even individual people who had provided data for genomic research. Similarly, the majority of AN respondents in a focus group study preferred restricted access to medical records and genetic information to protect individual and family privacy.<sup>31</sup>

Concerns about the violation of confidentiality were widespread, although more pronounced in younger respondents. In an interview study of 53 AI/AN individuals, participants expressed fear that researchers might violate their confidentiality.<sup>18</sup> Yet, while the risk of confidentiality breach decreased willingness to participate in cancer clinical trials for 1 group of older AI/AN individuals,<sup>22</sup> when investigators conducted a similar survey with college students, they found that confidentiality was an even more significant barrier to this group's participation in cancer clinical research.<sup>23</sup> In another study of AI/AN college students' likelihood of participation in health research, investigators found that perceived risks to confidentiality were among the strongest factors that decreased participation.<sup>38</sup>

## DISCUSSION AND CONCLUSIONS

AI/AN and NHPI communities experience some of the worst health outcomes of any group in the US<sup>42,43</sup> and are also underrepresented in health research.<sup>9,10</sup> We conducted this review of 21 studies involving 3234 AI/AN and NHPI individuals in order to learn what is known about these communities' views on health data privacy, identify gaps in the literature for future investigation, and to inform the research practices of investigators working with AI/AN and NHPI communities and their health data.

As mentioned previously, AI/AN and NHPI communities are diverse and heterogeneous. While we report on the range of privacy concerns that tend to arise for AI/AN and NHPI communities in health research based on available published literature, these should not be understood as representative of all AI/AN and NHPI communities. Thus, while results of this review may help investigators anticipate and address some common concerns in the secure collection, management and interpretation of AI/AN and NHPI individuals' health data, researchers should work to build relationships and establish dialogue about health data privacy with the Indigenous communities with which they work.

The most notable finding is while many AI/AN and NHPI individuals feel that health research may potentially benefit their communities, they are still reticent to participate due to a range of unresolved health data privacy issues involving the misuse of their biospecimens and/or data in ways that may harm themselves or their communities. This finding builds on observations from 2 recent US-based systematic reviews of individuals' perspectives on genetic privacy and broad consent and data sharing, respectively, which found that individuals from groups that are underrepresented in research had greater concerns about privacy and desired more control over the ways in which their data were used than their White counterparts.<sup>12,15</sup> In both reviews, AI/AN and NHPI individuals comprised a very small proportion of participants in included studies (4%<sup>12</sup> and 2.2%<sup>15</sup>) Thus, in reviewing privacy-related concerns specific to AI/AN and NHPI individuals in the context of health research, our review helps clarify some factors that may be contributing to the underrepresentation of this particular group in health research. In this vein, we found that 3 interconnected issues shape barriers to AI/AN and NHPI participation in health research, especially in studies involving biological specimens and data derived from those specimens: (1) insufficient informed consent processes (ie, materials that are inaccessible or not tailored to specific cultural or generational communities), (2) concerns over unapproved use/reuse of data and/or biospecimen, and (3) risks of breaches of confidentiality. Investigators conducting research with AI/AN and NHPI communities should seek guidance from local leadership and governance structures to ensure that materials, such as consent forms, are clear and accessible

and that activities pertaining to the collection and use of health data are not only more transparent for participants but connected to intentional practices of relationship-building between communities and researchers.

Another key finding from our review is that participants were concerned that biomedical research may result in stigma or discrimination of AI/AN and NHPI individuals and communities, a belief that is likely shaped by historical instances of research misconduct involving Indigenous communities. As such, future research and policy development regarding AI/AN and NHPI data privacy should focus on *collective* privacy risks (ie, risks incurred to communities rather than just individuals), as well as strategies to mitigate those risks. At present, regulations that guide IRBs are informed by the Belmont Report's (1979) principles of respect for persons, beneficence, and justice. Some scholars have noted that while these constitute an ethical foundation for conducting research with *individual* human participants, they fall short in protecting communities as a whole, particularly those with distinct cultural knowledge or practices that may be harmed by research.<sup>9,30,44,45</sup>

Our findings support the recommendation that researchers should also be held accountable to the beneficence of groups or communities when conducting research with Indigenous communities. This may be achieved by expanding the Belmont principles and informed consent processes to embody community-level risks and benefits, and/or consulting existing frameworks that articulate the collective rights of Indigenous Peoples, such as the United Nations Declaration on the Rights of Indigenous Peoples.<sup>46</sup> Participants in the included studies also raised concerns about the unapproved use and reuse of their biological specimens and/or data, and the interpretation and representation of findings involving those data. These insights further underscore the need for detailed informed consent processes that not only describe (verbally and written) all intended uses of biospecimens and data, but also provide opportunity for reconsent of secondary use of biospecimens and/or data aggregation beyond the scope of the original informed consent. Given our finding that the AI/AN and NHPI participants in this review are interested in participating in research that would benefit their communities, the realignment of research practices and protections to better communicate and facilitate those benefits may contribute to improved representation of AI/AN and NHPI communities in research.

The importance of community-level risks and benefits underscored by Indigenous participants in the included studies extends well beyond the US context. Similar sentiments were reflected by Indigenous Peoples across the globe according to a recent systematic review of barriers to participation in biobanking and genomic research that included New Zealand Māori, Aboriginal and Torres Strait Islanders, Native Hawaiians, Alaska Natives, and American First Nations.<sup>47</sup> In this review, investigators reported that Indigenous participants commonly understood biospecimens as an extension of the meaningful relationships they have to their ancestors and traditional lands, which has a significant impact on the ways they would like their specimens handled, the purposes toward which they would like them to be used, and understandings of who "owns" the specimens. In acknowledging the role of culture in shaping these views, investigators emphasized the necessity of community-engaged research partnerships, so that researchers are made aware of and respect culturally-specific practices involving biospecimens, a recommendation that frequently arose in the studies included in our review, as well. [Figure 3](#) summarizes key policy and research recommendations derived from our findings.

RESEARCH AND POLICY RECOMMENDATIONS	
<b>1. ESTABLISH TRUSTING AND COLLABORATIVE PARTNERSHIPS TO GUIDE RESEARCH:</b>	Investigators should work with local leadership and governance structures at all stages of research to ensure that research supports community needs and respects cultural knowledge and practices.
<b>2. ACCOUNT FOR BOTH INDIVIDUAL AND COMMUNITY-LEVEL RISKS:</b>	While extant oversight processes emphasize risks incurred to individuals, identify community-level risks and pursue specific strategies to mitigate them. We recommend: <ol style="list-style-type: none"> <li>The cultivation of policies to hold investigators accountable to individual and community-level risks (e.g., extension of the Belmont principles to communities), and</li> <li>Future, community-engaged research that explores the concept of <i>collective privacy</i> in more depth.</li> </ol>
<b>3. ENSURE TRANSPARENCY AND ACCESSIBILITY OF ALL RESEARCH MATERIALS:</b>	Recognize that materials approved by university Institutional Review Boards may not ensure that documents are written in ways that are clear and accessible to participants. We recommend that investigators work with local leadership and governance structures (even when not required by law) to ensure that materials use accessible language and thoroughly describe the goals and associated risks of a given research project.
<b>4. SUPPORT CAPACITY-BUILDING IN AI/AN AND NHPI COMMUNITIES:</b>	Support and extend current capacity-building efforts in AI/AN and NHPI communities, for instance: <ol style="list-style-type: none"> <li>Work collaboratively with AI/AN and NHPI participants in the collection, interpretation, and dissemination of their own data; and</li> <li>Invest in the training of future AI/AN and NHPI investigators.</li> </ol>

**Figure 3.** Summary of research and policy recommendations.

The most significant gap we observed in this literature is the general lack of discussion around the role of sociodemographic factors in participants' views of health data privacy perhaps, in part, because these factors were generally underreported as a matter of confidentiality. On the topic of gender, males were largely underrepresented in these studies. As 2 studies with an overrepresentation of females reported, a potential reason for this may be that the community agencies with whom researchers contracted to recruit participants tend to involve more women,<sup>28,29</sup> and that women are more willing to participate in qualitative research than men.<sup>29</sup>

Our study had several limitations. One major challenge of conducting this review was undertaking a topic as broad as *privacy*. As mentioned previously, others have written on the multiple meanings of privacy and the inconsistencies of what is meant by privacy in vernacular as well as academic uses of the term.<sup>12</sup> For example, investigators in the studies reviewed here did not define their usage of terms like privacy, confidentiality, and anonymity, and often used them interchangeably. While we offered our own working definition of *health data privacy* (the practice of maintaining the security and confidentiality of an individual's personal health records and/or biological samples and associated data, as well as the secure and approved use of those data), used broad search terms, and reviewed the reference lists of empirical studies as well as excluded dissertations, books, and book chapters to capture extant literature on related concepts, it is possible we may not have identified all relevant research. Additionally, our quality assessment was limited given that we were, in many cases, unable to access all materials necessary to thoroughly evaluate the study. For instance, several articles omitted interview or focus group protocols, or did not offer detailed information about their analysis plans.

The generalizability of this review is also limited by several factors. First, the heterogeneity of AI/AN and NHPI communities and

the relatively small body of literature addressing their health data privacy preferences limits the generalizability of our findings of US Indigenous Peoples at large. Additionally, numerous methodological approaches were used in the included studies, limiting their direct comparability. However, all studies were adequately focused on health data privacy or discussed health data privacy in their findings enough to permit some comparison. The included studies also featured many limitations themselves, further limiting the generalizability of this review. Finally, the investigators of the included articles frequently studied privacy views by asking participants about hypothetical research scenarios, rather than actual experiences and actions related to health research, and it is possible that participants' opinions may differ from their views and behaviors when confronted with actual versus hypothetical situations. It is difficult to avoid this limitation, as relatively few AI/AN and NHPI individuals may actually have experience providing data for health research, due to the underrepresentation of these communities in health research, in part, for the reasons we have described.

Given our findings that AI/AN and NHPI communities are more willing to participate in research led by Indigenous investigators, it is crucial that representation of AI/AN and NHPI researchers increases in medical and scientific fields. A 2015 study on diversity in clinical and biomedical research found that AI/AN and NHPI researchers comprise less than 0.4% and 1.2% of principal investigators on NIH research grants.<sup>48</sup> The same 2015 study found that minority researchers (including AI/AN and NHPI) are not funded equitably in comparison to White applicants, indicating that it is also crucial for these investigators to receive funding to support research involving Indigenous communities.

Despite these barriers, many AI/AN and NHPI communities are mobilizing to increase Indigenous participation in and governance of health research.<sup>2</sup> The Navajo Nation is currently working to de-

velop culturally-informed genetic research and data-sharing policies to lift a moratorium on genetic research.<sup>49</sup> Moreover, programs like the Summer Internship for Indigenous peoples in Genomics (SING) are training the next generation of Indigenous genomics scholars in the ethical conduct of genomics research in their communities,<sup>50</sup> and collaborations such as the Silent Genomes Project and US Indigenous Data Sovereignty Network are bringing together Indigenous scholars in the US and internationally to address strategies to maximize the benefits and mitigate the potential harms of genomics research to Indigenous communities.<sup>51,52</sup> Thus, as more AI/AN and NHPI communities participate in research, there should be continued emphasis on the development of policies to guide ethical research practices in studies of health data from AI/AN and NHPI individuals.

The goal of this literature review was to obtain an understanding of AI/AN and NHPI communities' perspectives on health data privacy in the context of health research and health care. Participants in the included studies showed an interest in various kinds of health research, particularly that which may prompt direct benefits to AI/AN and NHPI communities, but expressed significant individual and community-level concerns around privacy, including issues related to discrimination, confidentiality, and consent.

## FUNDING

The preparation of this manuscript was supported by NIH Grants R01 HL136835 (PI Ohno-Machado) and R01 HG008753 (PI Bloss). The opinions expressed in this article are the authors' own and do not reflect the views of the National Institutes of Health.

## AUTHOR CONTRIBUTIONS

Systematic review conception and design: RT, CB, and LOM; database searches and screening of abstracts: RT, CB, and CT; quality assessment scoring: RT, CB, JC; and manuscript writing, editing, and revision: RT, CB, CT, JC, NG, SC, JAS, LOM.

## ACKNOWLEDGMENTS

The authors would like to thank Mary Linn Bergstrom for her expert assistance with setting up and conducting the systematic literature review and Paul Spicer for his feedback during the development of this manuscript. We also thank the anonymous reviewers for their comments which strengthened this manuscript considerably. Finally, we thank the many Indigenous Peoples who participated in the studies we reviewed.

## SUPPLEMENTARY MATERIAL

Supplementary material is available at *Journal of the American Medical Informatics Association* online.

## CONFLICT OF INTEREST STATEMENT

None declared.

## DATA AVAILABILITY

Availability of data and materials: All data needed to evaluate the conclusions in the paper are present in the paper and/or the [Supplementary Materials](#). Additional data related to this paper may be requested from the authors.

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