

2-1-2013

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Lisa S. Parker  
*University of Pittsburgh*

Alex John London  
*Carnegie Mellon University, [ajlondon@andrew.cmu.edu](mailto:ajlondon@andrew.cmu.edu)*

Jay D. Aronson  
*Carnegie Mellon University, [aronson@andrew.cmu.edu](mailto:aronson@andrew.cmu.edu)*

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### Published In

Forensic Science International: Genetics, 7, 2, 221-229.

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Published in final edited form as:

*Forensic Sci Int Genet.* 2013 February ; 7(2): 221–229. doi:10.1016/j.fsigen.2012.10.002.

## Incidental Findings in the Use of DNA to Identify Human Remains: An Ethical Assessment

**Lisa S. Parker, PhD,**

Associate Professor of Human Genetics and Director of Graduate Education, Center for Bioethics and Health Law, University of Pittsburgh, 3708 Fifth Avenue – Suite 300, Pittsburgh, PA 15213

**Alex John London, PhD, and**

Professor of Philosophy and Director, Center for Ethics and Policy, Carnegie Mellon University. 5000 Forbes Avenue, Pittsburgh, PA 15213, Phone: 412-447-1793, Fax: 412-268-1440

**Jay D. Aronson, PhD**

Associate Professor of Science, Technology, and Society and Director, Center for Human Rights Science, Department of History, Carnegie Mellon University, 5000 Forbes Avenue, Pittsburgh, PA 15213

Lisa S. Parker: lisap@pitt.edu; Alex John London: ajlondon@andrew.cmu.edu

### Abstract

DNA analysis is increasingly used to identify the remains of victims of conflicts and disasters. This is especially true in cases where remains are badly damaged and fragmented, or where antemortem records are unavailable. Incidental findings (IFs)—that is, genetics-related information for which investigators were not looking—may result from these identification efforts employing DNA analysis. Because of the critical role played by family members of the missing in identification efforts, as well as the familial nature of DNA, identification initiatives employing DNA analysis are particularly prone to reveal IFs about familial relationships, such as misattributed paternity or false beliefs about sibling relationships. Despite forensic scientists' widespread awareness of the possibility of generating IFs, to date there has been relatively little explicit guidance about their management. This paper fills that gap. It offers substantive guidance about the ethical management of IFs in this context. To ensure that the analysis addresses actual needs and practices in the field, one author (JDA) conducted semi-structured interviews with key informants from six regionally diverse organizations involved in post-conflict or post-disaster identification efforts. The paper first describes how methods of DNA analysis give rise to IFs. Next, it explains the importance of developing an ethically justified general policy for managing IFs and discusses features of DNA identification efforts that are relevant to such a policy. Then it presents an argument in support of a general policy of nondisclosure—specifically, that considerations of fair access to the individual and social benefits of identification efforts, and the concern to minimize and fairly distribute the risks of participation, support a policy of nondisclosure. It concludes by considering some implications of this argument for the choice

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Correspondence to: Alex John London, [ajlondon@andrew.cmu.edu](mailto:ajlondon@andrew.cmu.edu).

Interest Disclosure: AJL is a member of the Steering Committee on Forensic Science Programs for the International Commission on Missing Persons.

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among scientific practices involved in using DNA analysis to identify human remains, as well as for managing non-genetic incidental findings.

## Keywords

incidental findings; ethics; DNA identification; missing persons; disaster victim identification (DVI)

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Over the past two decades, DNA analysis has been increasingly used to identify the remains of victims of conflicts and disasters [see, e.g., 1–15]. Although there are many techniques that investigators can use to facilitate the identification of missing people (e.g., fingerprinting, forensic odontology [dentistry], and forensic anthropology), in cases of badly damaged, fragmented remains, or where antemortem records are unavailable, DNA is often the best way to make a positive individual identification.

Despite its utility in identification efforts, DNA analysis also has the potential to generate incidental findings (IFs)—that is, to discover genetics-related information for which investigators were not looking [16,17]. Although different methods of identification may produce other kinds of IFs—for example, information about the circumstances of the deceased’s death—because of the familial nature of DNA, its analysis is particularly prone to reveal IFs about familial relationships, such as false beliefs about parental or sibling relationships. For this reason, the analysis that follows focuses primarily on IFs that relate to discrepancies in kinship.

The prospect of discovering IFs in the course of identifying remains raises several ethical questions. Chief among these is whether and to whom they may be disclosed. How to record, store, and safeguard (or, alternatively, make publicly available) such findings are also important issues. These are policy-level questions that need to be addressed in advance of implementing identification efforts for two main reasons. First, policies established to manage IFs need to be disclosed as part of the effort’s informed consent process. Second, decisions about which scientific practices to adopt in conducting DNA identification can influence not only the success of the identification effort, but also the likelihood or frequency of discovering IFs.

Despite widespread awareness among forensic scientists of the capacity of different techniques to generate IFs, there has been relatively little explicit guidance about how to manage the ethical issues associated with such findings. For example, a recent National Institute of Justice (NIJ) report lists as one of the major lessons learned from the DNA identification effort undertaken after the 9/11 attacks that: “DNA analysis may uncover situations in which biological relationships are not as reported. In such cases, the laboratory must have a policy. It may be advisable to consult with a bioethicist...” [1–8, page 52].

The goal of this paper is to analyze the ethical issues that arise from IFs in identification efforts and to provide substantive guidance about an ethically justified policy to manage them. In particular, we argue that a policy of nondisclosure is supported by considerations of fair access to the individual and social benefits of identification efforts, and the concern to minimize and fairly distribute the risks of participation.

We begin by describing how the methods of DNA analysis give rise to IFs. Then we explain the importance of developing an ethically justified general policy for managing IFs and discuss features of DNA identification efforts that are relevant to crafting such a policy. We next argue that considerations of fairness and the minimization of risk support adopting a general policy of not disclosing IFs. We conclude by considering implications of this

argument for the choice among scientific practices involved in using DNA analysis to identify human remains, as well as for managing non-genetic incidental findings.

To ensure that our analysis addresses actual needs and practices in the field, one of us (JDA) conducted semi-structured interviews with key informants from six regionally diverse organizations involved in post-conflict or post-disaster identification initiatives reflecting a range of case loads and mandates. Because of the sensitivity of this issue, our informants agreed that it would be best not to reveal their names or their organizations, or to include details of any specific cases.

## Two Methods of DNA Analysis in Identification Efforts

Although practitioners in field of DNA identification will be intimately familiar with the scientific aspects of the identification process, others interested in the policy questions addressed in this paper may benefit from this brief description of two methods of DNA identification.

When human remains are fragmented or badly damaged, DNA analysis may be the only feasible way to make a positive individual identification. No two human beings have precisely the same DNA. Each of us carries minor variations in the structure and sequence of our DNA that make us genetically unique individuals, although it may be difficult in practice to distinguish the DNA of identical twins. One method of using DNA to identify human remains relies directly on this uniqueness of an individual's genetic profile. "Direct matching" involves comparing DNA extracted from unidentified human remains to DNA from biological material found on personal items, such as toothbrushes, hairbrushes, razors, or pieces of clothing, known to have been used by a person who has gone missing. A match occurs when the genetic profiles from the human remains and that obtained from a personal item (the "direct sample") are identical. Direct matching was used in approximately two-thirds of all identifications in the aftermath of the September 11, 2001 World Trade Center Attacks. Because most of the victims were living in stable environments before their deaths, and because the attacks did not destroy their homes or other places where they might have had personal effects, relatives could quickly provide authorities with items from which DNA samples could be obtained [18].

When direct samples from personal effects are not available, investigators may rely on "kinship matching." This second method compares DNA profiles from human remains with DNA profiles of known biological relatives of victims (generally referred to as "reference samples"). This identification method relies upon the fact that the variations in our DNA that make each of us genetically unique are passed down to us in various combinations from our parents and are most likely to be shared by other individuals who are closely biologically related to us. Kinship matching involves calculating the probability of biological relationship of the deceased to specific living individuals. This calculation is based upon identifying DNA markers that are shared among the reference samples and the human remains. This method works well when DNA samples are available from close relatives. It is less effective when several members of the same family are missing or when it is difficult to obtain DNA samples from the victim's closest relatives.

Kinship matching is the primary method used to identify the remains of victims of the conflict in the former Yugoslavia [14]. Given the widespread displacement of persons during the conflict, the fact that entire families were sometimes missing, and the amount of time that elapsed between the conflict and identification efforts, direct matching was often not feasible. In its work relating to the Western Balkans, as of September, 2012, the International Commission on Missing Persons (ICMP) has produced scientifically conclusive DNA identification matches on 16,773 persons from among the estimated 40,000

persons missing as a result of that conflict. To facilitate this effort, the ICMP has compiled a database of DNA profiles from 89,980 relatives of 29,187 missing people [19].

Both direct and kinship matching methods rely on relatives of the missing to supply samples for DNA analysis. Samples can be collected in one of three ways: 1) following mass fatality events, centers may be established where families can bring their missing loved ones' possessions and donate a reference sample to be used for kinship matching; 2) relevant domestic or international agencies can engage in outreach programs to ask people to contact them to set up appointments to bring direct samples in and have reference samples taken at specific locations or through designated agents; or 3) rarely, collection of samples can be compelled through legal processes.

When donating reference samples, relatives typically supply an account of how they are related to each other and their missing loved one. Thus, kinship matching can reveal discrepancies between the kinship relationships reported by living relatives and relationships revealed by DNA analysis. According to our interviews, the most common DNA-related IF involves discovering discrepancies between the reported social relationship among siblings and their genetic relationship revealed by donated reference samples. In some cases, there may be no genetic relationship at all, suggesting previously undisclosed adoption. In other cases, those who believed they were full siblings have only one parent in common, indicating misattributed parentage. Less common is misattributed paternity (i.e., when a man is erroneously believed to be the biological father of a particular child). It should be noted that direct matching can also reveal IFs if family profiles are used to validate the DNA from a personal item.

## The Normative Framework of Efforts to Identify Human Remains

When kinship discrepancies are uncovered, investigators may face what seems to be a moral dilemma. Investigators may feel personally uncomfortable knowing information about a family that family members themselves do not know. Moreover, kinship discrepancies complicate the identification process and may reduce the probability of successful identification of remains. In the case of kinship matching, for example, the finding that a reported family member is not a biological relation may limit the statistical confidence with which DNA from a missing person can be determined to match a family profile. As a result, it may be desirable to request DNA samples from additional family members. If family members want to know why additional samples are necessary then investigators face a difficult choice. On the one hand, they could be transparent and truthful, disclosing information that can have potentially serious negative consequences for family members. Or, in order to avoid risking harm to families, investigators could decide to evade questions, hide information, or engage in outright deception. To some degree this dilemma can be mitigated by informing individuals during the consent process that IFs of this nature can occur and disclosing how they will be handled. Requiring that participants be asked to give their voluntary, informed consent before participating in identification efforts—and respecting their refusal if they decline—affords people fundamental respect and protection. This doctrine of informed consent recognizes the right of individuals to control access to their bodies (and private information) and empowers them to protect their own interests by refusing or consenting to participate [20]. Informed consent serves individuals' autonomy and welfare interests. Only by being informed of the policies, risks, and benefits of the identification process can relatives of the missing make an informed participation decision. Thus it is critical that they be informed of both the risk of IFs and policies regarding them.

However, including this information in the informed consent process does not settle the prior policy question of how IFs should be handled once they are discovered. That family

members consent to participate under a particular policy does not necessarily mean the policy in question is fair or equitable. At best it shows that they are willing to accept the risks associated with a policy in order to access participation's myriad potential benefits. Because these benefits can be particularly important to families, it may be the case that family members are willing to participate under terms that are not fair, or not as fair as those that could be offered under alternate policies. Similarly, while the informed consent process respects the autonomy rights of families who refuse to consent under a given policy, it does not follow that the conditions under which they refused to participate were fair. Therefore, although investigators must seek family members' free and informed consent prior to their participation, policy makers must also ensure that the policy for dealing with IFs adequately balances the conflicting moral considerations that arise from the discovery of such findings.

It is our contention that an acceptable policy for managing IFs must ensure that family members participate in the identification process on terms that are fair, that demonstrate adequate concern for their welfare and autonomy interests, and that minimize risks while affording equitable access to the benefits of identification. In order to understand what terms of participation might meet these criteria, it is necessary to understand: 1) the individual and social goals that are advanced by the DNA identification process; 2) the risks that participants encounter from participation in general, and from IFs in particular; 3) the practical steps that might be taken to minimize these risks, and 4) how general policies regarding the disclosure of IFs might affect the distribution of such risks and potential benefits. We now turn to a discussion of each of these points and to the respects in which they support a general policy of nondisclosure.

## The Goals and Benefits of Identification Efforts

DNA identification efforts have been carried out in a wide range of contexts to advance a diverse mix of individual and social goals. Most, but not all [21], efforts to identify human remains serve the humanitarian goals of confirming the fate of the missing and repatriating remains so that families and loved ones can perform funerary rights [see, e.g., 22,13,14]. Identification efforts often directly advance important psychological and social interests of individuals. The International Committee of the Red Cross (ICRC), for example, recognizing that "the families of missing people ...live in extreme emotional anguish because of the uncertainty surrounding their loved ones" and seeks to provide "psycho-social support during their long wait for answers and, eventually, closure", with the identification of remains sometimes serving to provide that closure [23]. Uncertainty about the fate of a loved one can effectively trap family members between the desire to move forward and the fear that doing so represents giving up hope and abandoning a loved one who, having escaped death, might someday return. While other members of the community move forward, families of the missing may remain psychologically connected to the traumatic event, creating a dynamic in which psychological pain is compounded by social isolation [24]. Identification efforts can directly address feelings of exclusion and isolation because they represent a concrete social activity in which the status of a loved one as missing is emphasized. Similarly, successful identification of missing loved ones eliminates the uncertainty associated with their whereabouts, enabling families to perform funerary rights, to move forward psychologically, and to access the social benefits that often attend confirmation of a relative's death [24]. These may include the receipt of a death certificate and the ability to remarry, to sell or distribute property, to initiate legal claims, or to exercise rights associated with insurance or other forms of compensation. Recognizing these benefits of identifying the missing and returning remains to family members, the First Protocol Additional to the Geneva Conventions specifically provides that parties to armed conflict should "facilitate the return of the remains of the deceased ... to the home country ... or ...



the next of kin [25]. The ICRC specifically includes victims of internal violence, as well as international armed conflict, as individuals entitled to these benefits [26].

Identification efforts are often undertaken to advance an array of important social goals as well. The massive effort to identify the missing in the former Yugoslavia in the aftermath of the wars of the 1990s, for example, was initially undertaken by international actors—including the U.S. and Dutch governments and non-governmental organizations such as ICRC and US-based non-governmental organization (NGO) Physicians for Human Rights (PHR)—to facilitate reconstruction and reconciliation efforts in the post-conflict context [14]. Today, DNA identifications are increasingly used by the International Criminal Tribunal in the former Yugoslavia to hold parties accountable for their violations of international human rights, most recently in the case of Radovan Karadžić [27]. The South African Missing Persons Task Team, a government agency under the auspices of the National Prosecuting Authority, seeks to resolve missing persons cases revealed during the Truth and Reconciliation Commission process in order to contribute to the transitional justice process [22]. The Guatemalan Forensic Anthropology Foundation, a government-chartered NGO, has a dual mandate to clarify the historical record for future generations and to assist the government in prosecuting crimes against humanity that took place during the 1960–1996 civil war [28]. The Argentine Forensic Anthropology Team was formed in 1984 to provide evidence for criminal prosecutions against military officials who had committed human rights abuses against political activists during the “Dirty War,” but morphed into an organization that identified missing people for the sake of families when the democratically elected president of the country declared an end to such legal actions in 1986 [29]. PHR provides independent forensic expertise to collect evidence of violations of human rights and humanitarian law around the world. The organization endorses the view that people have “the right to know the truth, and to have history recorded accurately in order to establish a historic record grounded in science and resistant to revisionism” [30].

Identification efforts undertaken in the wake of natural disasters or accidents serve a similar range of individual and social ends. Returning remains to surviving relatives and their communities is a humanitarian act through which governments and international aid organizations evidence care and respect for the living and the dead [14]. In addition, efforts undertaken in the wake of transportation accidents, such as airplane crashes, may be mandated by law or as part of civil or criminal liability proceedings. Similarly, many countries have laws that require law enforcement agents or regional medico-legal examiners to investigate deaths in the wake of natural disasters. Identification efforts thus contribute to systems of accountability that are enshrined in criminal and civil law, and are often necessary for families to exercise a range of social and legal rights. These include rights associated with criminal and civil relief, compensation, and powers associated with marriage and property rights.

Thus, identification efforts are grounded in multiple values, including humanitarian efforts to evidence *respect* for the dead and their relatives, to afford *psychological benefit* to living relatives, and to provide the evidentiary basis for them to receive the *material benefit* of humanitarian aid or legal compensation. Various types of *justice*—grounded in international human rights, transitional, criminal, civil, or compensatory justice frameworks—are also served by different identification efforts. Finally, the value of *establishing the truth* animates some identification efforts (e.g., with regard to the historical record in the Western Balkans, South Africa or Guatemala, or in the interest of aviation safety). Frequently these values and goals are mutually reinforcing or complementary, but it is possible for them to conflict. It is necessary then, that they be carefully balanced or that priority among them be established. Furthermore, pursuit of these goals and benefits must be balanced against, and ideally outweigh, the risks associated with participation in identification efforts.

## Risks of Participation

In order to bring about the individual and social benefits associated with identification efforts, individuals and groups must participate in a process that entails some risk for them. These risks may stem from mere participation in the process, proof of relationship to the missing, discovery of IFs, or other aspects of the identification effort. Moreover, the probability and magnitude of the potential harms associated with participation may differ across individuals. How much risk is presented may depend both on the sociopolitical, economic, and cultural context in which such efforts take place and on the individuals' particular situation within that context. As a result, individuals seeking to bring about the same personal benefits, or to contribute to the same social benefits, may nevertheless face substantially different risks from contributing personal effects of the missing or their own DNA samples to identification efforts.

This heterogeneity of risks stems partly from the heterogeneity of sociopolitical, economic, and cultural contexts in which identification efforts take place and particular features of the effort. For example, in some cases, the personal effects of the living or DNA samples from families are collected by agents of the state, such as police or the military. In other cases, they are collected by members of international organizations that operate outside of the jurisdiction of domestic authorities. In some cases, identification efforts are undertaken with the strong political support of the domestic government and are supported by strong legislative protections. In other cases, they are undertaken in sociopolitical contexts in which individuals and entities that had previously committed human rights violations still hold power or wield political influence, or in which there may not be strong legal protections in place to protect individual rights. Moreover, identification efforts have been conducted in high-income settings with a robust infrastructure and in low and middle-income contexts characterized by more pervasive resource scarcity.

Many variables have profound implications for the well-being of living relatives of those who are (or are not) identified: the current stability of the government and institutional structures, the likelihood of future stability, and the degree of commitment to protection of citizens' civil and human rights, as well as the financial resources committed to identification and subsequent political and legal actions.. In some contexts, as with the World Trade Center Attacks or a plane crash, identification has primarily psychological and financial implications for the living. In others, identification of remains at a particular site, indicating the deceased was on a particular side of civil conflict, could subject relatives to violent reprisals or social shunning. Records of identifications and genetic findings that are secure under a current political regime may become insecure with political change, or may be used by another regime as political tools.

Another source of variability in risk stems from intragroup variations in social, economic, and political status. Despite the heterogeneity of identification efforts, it is often the case that victims are disproportionately poor or disenfranchised members of minority groups. The general vulnerability of victims magnifies the risks associated with their relatives' participation in identification efforts. Similarly, gender differences and cultural norms often intersect to place the interests of women at significantly greater risk than male counterparts from participation in identification efforts. In any family, a finding of misattributed paternity can be psychically disturbing and socially disruptive, but in some cultures proof of adultery or rape can imperil a woman's life.

Thus, features of the identification process and its sociopolitical context, as well as cultural features—such as the status of women, or the social acceptability of adoption, non-biological relatedness, or extramarital relations—affect not only the probability and



magnitude of risks, but also their distribution among prospective participants in identification efforts.

## Fair Terms of Participation

DNA identification is a fundamentally social activity in the sense that it depends on the willing participation of multiple individuals. Their confidence in the enterprise must be maintained by fair policies and practices, including precautions that minimize the risks of participation for individuals and communities.[31] In kinship matching, for example, multiple individuals must donate their own genetic material in order to construct a set of profiles that can be compared to the DNA profiles taken from the remains of the missing. In direct matching, family or friends of the missing must come forward with personal items and sometimes contribute DNA to validate reference samples.

Each individual may face a different mix of benefits and risks from participating in the matching process and, therefore, may have a different estimate of the reasonableness or importance of contributing. For close relatives of the missing (e.g., spouses, parents, or children), the potential for substantial psychological or material benefits may outweigh fairly significant risks of participation. Especially when biological distance from the missing is accompanied by more attenuated social ties, more distant relations (e.g., cousins, aunts or uncles), may not place such high value on identification.. Similarly, entire families and communities can differ in their estimates of the importance of fostering the identification process and therefore differ in their willingness to accept social risks that attend participation. Yet, for any particular individual the possibility of benefit depends upon the willing participation of others. That, in turn, depends on their willingness to accept associated risks. This fundamentally social nature of identification efforts, coupled with the individualized degree of risk and potential benefit associated with participation, has important implications for development of a policy regarding management of IFs.

In general, the prospect that participation in the identification process might reveal kinship discrepancies or mismatches is likely to be viewed by participants as a risk with potentially serious consequences. Moreover, members of the larger community may also be concerned that revelation of kinship mismatches, such as misattributed paternity, could stigmatize or exacerbate negative stereotypes of the entire community or subgroups within the community. It is also worth noting that fear or concern about the prospect of such findings is likely to be more widespread than the actual findings themselves. The reason is simply that as a matter of statistics and biology there are likely to be more people who have reason to be concerned about the possibility of kinship discrepancy attributable to extramarital sexual relations than the number of pregnancies actually resulting from such relations. The risks of participating in an identification effort, including the risk of the discovery of a kinship discrepancy, are not distributed evenly across society or even among those who stand to benefit from the effort.

The asymmetric distribution of risks and benefits from DNA identification provides strong support for adopting a policy of nondisclosure. As recognized by the ICRC, in efforts to identify the missing, information and particularly genetic information “is a powerful tool when used correctly and dangerous when misused” [26, page 9]. A policy of not disclosing IFs would reduce the risks of participation for family members and communities. Reducing the risks of participation in this way would also reduce a potential hurdle to the participation of socially and biologically more distant relatives who might view the risks of participation as unreasonable in light of what they might perceive as relatively modest benefits.

In some societies genetic testing to establish (or rule out) paternity or to learn about one’s genetic relationships or ancestry is available commercially, and is utilized for reasons

ranging from curiosity to fulfillment of a court order or access to financial support. Although the commercial availability of DNA analysis of relatedness indicates that some people value such information, it does not follow that the *unanticipated* discovery of such information in the course of DNA identification will be regarded by participants as a benefit. Some individuals might value learning of IFs and view the possibility as a potential benefit of participation, while others view such revelations as a serious risk of participation.

It may appear that allowing individuals to choose during informed consent whether they want to receive such information if it is discovered would better address this diversity of attitudes. However, the information that would be disclosed materially concerns more than just the interested party. It reveals potentially sensitive information about others, including family members who chose not to participate in the identification initiative because they do not wish to be associated with it or are seeking to hide knowledge that might upset family dynamics.

It may be thought that if all members of a specific family agree that any IFs discovered should be disclosed to them, then disclosure should be permitted. However, this option raises serious questions about the degree to which particular family members could object to the disclosure of such information without putting themselves at increased risk of suspicion of infidelity or other stigmatized behavior. Investigative teams would seldom be in a position to determine whether undue pressure to agree to such disclosure was exerted by some family members upon others.

Thus, while a policy of not disclosing kinship mismatches is unlikely to deter those who would value the disclosure of such information, a policy of disclosure could either prevent some individuals from participating, or result in some individuals participating under threat of harm from a failure to agree to the disclosure of such information, should it arise. As a result, a policy of nondisclosure would maximize the willingness of individuals to participate in identification efforts.

Moreover, in some communities social authorities might view identification efforts and discovery of kinship mismatches as a welcome opportunity to enforce social norms regarding fidelity and adultery. It is likely, however, that such views will correlate strongly with increased risk to other individuals, especially those whose conduct breached the relevant norm. Those who would be subject to such policing are most likely to be individuals who are already socially vulnerable or marginalized, for example, women. When this is the case, a policy of disclosing IFs related to kinship discrepancies could provide a pathway for exacerbating social inequalities and relationships in which power and authority are used to the disadvantage of socially vulnerable or marginalized people.

For all of these reasons, the importance of fairly balancing the risks and potential benefits of the identification process strongly supports a policy of nondisclosure. Such a policy better promotes the availability of the direct psychological and material benefits associated with identification of the missing to more people, including the most vulnerable individuals and groups, while imposing the fewest burdens on participants. A policy of nondisclosure increases equity in the distribution of risks by eliminating a potential pathway through which the identification process could be used to disadvantage socially vulnerable individuals or groups. Further, it promotes the social goals and maximizes the social benefits of identification efforts by both minimizing the frustration of those goals by individuals' nonparticipation and promoting the effectiveness of the effort itself. A policy of nondisclosure also reduces the opportunity for identification efforts to be co-opted for the unjust persecution of individuals or groups.

It might be argued that not disclosing kinship mismatches is contrary to the social goals of truth and transparency that animate at least some identification efforts. While not reporting discovery of mismatched kinship may seem irrelevant to the goal of identifying plane crash victims and creating an accurate aviation safety report, it may seem that holding back *any* information is antithetical to a post-conflict identification effort's mandate to seek the truth and establish an accurate historical record. Should setting straight the historical record extend to correction of false beliefs among reference sample donors about their biological relationships?

In cases where conflict or human rights abuse directly involves forced or coerced sexual encounters, or the removal of children from their families of origin and placement with other families, discovery of kinship mismatches may indeed be integral to the goals grounding the identification effort [32, 33]. In such cases, it may not be appropriate to class findings of kinship discrepancies as "incidental" to the identification effort, since they fall squarely within its goals and mandate. In most other cases, however, findings of kinship discrepancies are likely to fall outside of those goals. Even maximally truth-focused mandates, such as those of the South African Missing Persons Task Team and the Truth and Reconciliation Commission, or the Guatemalan Forensic Anthropology Foundation, seek to create an accurate historical record within particular spheres pertinent to past violations of human and civil rights. Not every discoverable truth about either the dead or the living is pertinent to the public interest in the historical record. Unless violations or distortions of familial relationships are a central focus of the larger social goals of truth and reconciliation, kinship mismatches in DNA identification efforts should be treated as private information, not related to the conflict, and therefore should not be made part of the historical public record.

Therefore, in light of the previously detailed considerations supporting the nondisclosure of IFs involving mismatched kinship, we argue that a general policy of nondisclosure should be adopted. Departures from that policy for the sake of establishing an accurate historical record must be justified by the direct relevance of the kinship-related finding to the violation of human or civil rights.

It is important to articulate in advance of any identification effort how specific findings of kinship discrepancy will be regarded vis-à-vis the mandate of establishing an accurate historical record. Will they be regarded as incidental to the identification effort or as an integral part of its larger social mission? Anticipatory development of a policy permits individuals to be informed during the consent process about how such findings will be handled. This process avoids individual kinship-related discoveries being treated differently depending on the particular investigator, family member, or circumstances involved, thereby avoiding ad hoc or arbitrary decision making, or the appearance thereof. In the absence of policies governing which findings will be disclosed to participants or made accessible in public records, individual findings are managed according to the values, priorities, beliefs, and feelings of comfort or discomfort of individual investigators (or investigative teams) (JDA interviews). The absence of a policy not only burdens individual investigators with making such "judgment calls," but also may result in inconsistent and thus unfair management of findings. Fairness requires that findings of similar status (incidental or integral) be managed similarly. Adopting policies in advance thus promotes fairness and allows individuals to protect their interests during the informed consent process. Once these policies are adopted, it is important to uphold them in all cases. Adopting a general policy of nondisclosure, but responding affirmatively to individual requests, would unfairly afford perceived benefit to those who are sufficiently assertive, well-off, or well-connected to make an effective request for such information.

## Nondisclosure of IFs and Scientific Practices

So far we have argued that a policy of not disclosing IFs is supported by a variety of concerns regarding fairness in the distribution of risks and benefits that flow from identification efforts, as well as the importance of ensuring that those efforts will not be co-opted for other ends. These arguments have important implications for policies regarding the format, distribution, and storage of identification reports and the storage of raw data associated with DNA analysis. They are also relevant to the choice among available scientific practices for collecting and analyzing DNA samples. We now argue that considerations that support not disclosing IFs to participants similarly support adopting practices that avoid or substantially mitigate either the discovery of IFs or their inadvertent public disclosure or accessibility.

### DNA analysis

Any practice that involves creating a complete family pedigree before searching for matches between unidentified remains and reference samples increases the likelihood of discovering IFs. There are two main situations in which this occurs. The first is when investigators compare the DNA from unidentified remains to DNA profiles of a specific family unit in order to test the hypothesis that this is their missing relative (e.g., based on information obtained from police records or eyewitness testimony). Because the family is being treated as a unit, any discrepancies in kinship will be obvious to the investigator when they compare DNA profiles of purported relatives to each other and to the unidentified remains.

The second situation is the use of a technique called “reference sample validation.” Recommended by The American Association of Blood Banks [34], reference sample validation involves making kinship calculations among family reference samples prior to any attempts to match with human remains in order to ensure that reported social pedigrees agree with biological kinship determinations. Discrepancies between kinship as reported and as verified by DNA analysis are investigated, and only validated samples are included in the reference sample database. Reference sample validation is recommended because it is seen as maximizing the possibility of identifying missing people, yet it guarantees that cases of inconsistent pedigree will not only be identified, but investigated and clarified.

Only two of our six key informants—both from organizations with relatively small case loads—reported employing the practice of reference sample validation. Others either found the process too resource intensive and time consuming, or specifically avoided it because it unnecessarily opens up the “can of worms” of IFs. Most larger identification efforts avoid reference sample validation by loading all reference profiles into a single database without validation and then running the DNA profiles from unidentified remains against this entire database in order to search for close matches (JDA interviews).

Assuming the profile from the remains matches enough reference samples to make a definitive identification, no further investigation of familial relationships is necessary. It is only when investigators fail to reach the required level of scientific certainty (which varies according to context and from organization to organization) with the information they have that familial relationships may need to be further examined. Routine (as opposed to case-specific) reference sample validation increases the likelihood of discovering kinship discrepancies and thus exacerbates the ethical concerns previously outlined. Therefore, the practice should be employed only when it is coupled with a clear process to prevent the disclosure of IFs to family members.

## Oversampling

Other practices may not affect the frequency of *discovery* of IFs, but influence whether they are *disclosed* to participants once discovered. One of the most commonly used strategies to avoid having to disclose detected IFs to DNA donors is to request more reference samples than may be strictly sufficient to identify a missing person during the initial collection. Oversampling provides redundancy in case some samples are not usable, whether because they become contaminated, or because of discrepancies between social and genetic relationships. It is an advantage of this approach that in such cases, investigators can use additional reference samples already on hand without having to return to the family to collect additional DNA samples. By eliminating the need to return to families for additional samples, oversampling obviates the need for investigators to explain to families why a match could not be made with those already collected.

Oversampling is most feasible when there is easy access to family groups, as well as adequate funding since traveling to family members, obtaining informed consent, collecting samples, and cataloging them can be resource-intensive activities. Investigators in identification efforts involving more dispersed family members, or requiring expenditure of significant time and resources in gathering samples, tend to collect fewer samples up front and then go back to families when necessary (JDA interviews).

From our interviews, we learned that when discovery of IFs initially prevents an identification and investigators must request additional DNA from families, they often give vague reasons, such as concerns about the quality of DNA samples already taken or their inadequacy for statistical calculations.. In the case of blind matching, when matches emerge that are partial or do not reach acceptable levels of statistical confidence (and they cannot be resolved with existing samples), some key informants report that they “quietly” reach out for additional family members to donate reference samples, by stating that they want as much genetic material as possible to ensure that a match can be made (JDA interviews).

We recommend adopting a policy of not disclosing a case-specific reason (such as mismatched kinship) when it is necessary to request additional samples from families. This is especially important when oversampling is infeasible. The policy might include providing a standard, scripted reason for the request, such as “We were unable to establish a match with adequate statistical confidence using the previously collected reference samples; therefore, we need to request samples from additional family members.” During the informed consent process, participants should be informed of the possibility that the participant or other family members may be (re)contacted to seek additional samples if those initially collected do not afford a match. It may be further explained during informed consent that this need may result from a range of reasons including sample contamination, laboratory error, family structure, and reporting error, and that the specific reason will not be disclosed to those families recontacted.

## Reporting/recording practices

Errors or miscommunication in reporting and recording family pedigrees are a major source of mismatches between social and biological kinship. Notions of family relatedness may differ considerably between the scientists conducting the DNA testing and the communities in which they work, or between those collecting the samples and information and those supplying them. In many societies the term “aunty” is used to refer not just to the sister of a parent, but also to close family friends. Similarly, in many parts of the world, the concept of the “cousin brother” —i.e., that the son of your uncle is not only your cousin, but also your “brother” —may complicate reporting and recording of family relationships. It is advisable to clarify the terms used to report familial relationships at the inception of the identification



effort. This may minimize confusion and the need to recontact families due to a “discovery of mismatched kinship” that is really due to miscommunication. If the people recording genealogies when reference samples are being collected are unaware of these culturally unique kinship concepts, they risk not knowing to ask the important question of “which kind of brother is he?” Engaging the services of trained genetic counselors to manage the data and sample collection process can mitigate these problems to some extent [35–36].

### Result reporting practices

Practices surrounding the reporting of identifications influence the likelihood that discovered IFs are subsequently, and sometimes inadvertently, revealed. Issuing unnecessarily detailed match reports to family members—or even retaining them in files that are available to family members or that may become public—may result in the inadvertent disclosure of IFs. Returning detailed information about the information used to make a match may lead particular individuals who donated reference samples to wonder, for example, why they are not included in the final match report or why others are. The best way to avoid revealing IFs involving discrepant relationships is not to include raw genetic data on the match report, but rather simply state that an identification has been made with a particular level of statistical confidence, likelihood ratio, or probability of a false match.

Even internal records may result in the eventual revelation of IFs if their security and privacy are breached, or if other investigators utilize pedigrees or samples annotated with IFs and inadvertently disclose them. The AABB guidelines, for example, recognize that validated samples that do not comport with reported social kinship pedigrees can still be used in the matching process by placing them in their position in the pedigree according to biological rather than social information. The AABB notes that when doing so, “it is extremely important to make sure that the entity that is using the report to make the final identification understands the modifications that were made and any other possible alternative explanations, and adheres to appropriate policies for genetic data protection to avoid additional harm to families” [34, page 16].

The ability of those involved in identification efforts to protect families from potential harms associated with disclosure of an inconsistent pedigree hinges critically on their ability to safeguard genetic samples and data. Yet individuals and organizations directly involved in identification efforts—obtaining donor consent, procuring samples, and analyzing them—typically lack the broader authority and material ability to safeguard these materials and protect individuals’ privacy. Even when particular sensitive information is not communicated to families, it remains in the case files of the organizations charged with identifying the missing. When this evidence is provided to courts—for example, in support of compensation claims or in the context of human rights prosecutions—it becomes part of the legal record, and is therefore subject to various forms of subpoena and discovery processes. When identification efforts—are part of truth commissions or other forms of national history documentation, the records of these endeavors are sometimes considered aspects of national heritage. As such, no matter what the sensitivity of the information included in them, there is a chance that they will one day be made public, leading to possible revelations of IFs (JDA interviews).

Perhaps the most effective way to reduce the risk that IFs will be disclosed at some future point is to avoid recording them. Although this may be advisable in some contexts, it may also interfere with the validity of the scientific process and the legitimate interest in being able to oversee and monitor the quality of the identification process. As such, we recognize that there may be limits on the ability to avoid documenting IFs while preserving the integrity of the scientific process. During the informed consent process, potential participants should be told that if IFs are discovered, they will not be disclosed, but that



there is a chance that they could be made public in the future. This may empower some prospective participants to protect their interests as much as possible. Because of the familial nature of DNA, however, even those family members who refuse to participate (or are never even invited to do so) may be affected by the findings of DNA analysis (either IFs or the remains identification itself). Therefore, to the extent possible, investigators should implement practices that avoid recording IFs and especially avoid the permanent recording of such incidental information. Along these lines, the ICRC advocates the destruction of DNA samples and profiles “after they have served the purpose for which they were collected, unless required for related purposes” [37].

### Extending the Analysis to Non-genetic IFs

The analysis that we provide above focuses specifically on IFs related to discrepancies in kinship. The extent to which it applies to other kinds of IFs depends on how other IFs relate to the considerations that drive the analysis we have provided. One consideration that drives our analysis concerns the extent to which IFs about kinship discrepancies reveal information that is social in nature, in that it represents sensitive information about more than one person. Another consideration concerns the way that the social nature of this information creates asymmetric risks between the parties whose information may be revealed and the potentially conflicting interests of these parties in learning this information. Of particular concern is the fact that these differences in risks and conflicting interests regarding disclosure cannot be eliminated by the mechanism of informed consent. Finally, our analysis relies heavily on the importance of maintaining the integrity of the identification enterprise and the way that disclosure of IFs regarding kinship may permit that enterprise to be coopted for illegitimate purposes or otherwise undermine trust in the enterprise.

Some incidental findings that relate to genetic information may reveal health related information specifically about the donor. Detecting deletions on the Y chromosome, for example, may indicate infertility on the part of the donor. If more advanced technologies, such as genomic sequencing, are utilized to identify human remains, the possibility of discovering IFs of reproductive or health-related importance will expand. Despite the apparent utility of sharing information of health importance, revealing this information may have differential social risks for different persons depending on their familial, cultural, and social circumstances. Moreover, as has been found in other contexts, not only the degree of risk, but also the magnitude of possible benefit from such health-related IFs depends on factors that investigators cannot be expected to anticipate [38]. Therefore, maintaining fair terms of participation in identification efforts as well as the scientific integrity of the enterprise and the public’s confidence—supports a policy of nondisclosure of these IFs as well.

Similarly, identification efforts may produce a range of incidental findings beyond those relating to health, social kinship or genetic relatedness. In the process of identifying human remains, investigators may discover graphic photographs of the deceased, previously unknown information about the case from police or other files, or information about the person’s activities immediately prior to his or her disappearance. It is also possible that investigators will discover private, personal information about living relatives of the missing or other parties. For instance, by stepping forward as a witness to an abduction or accident, a person may inadvertently disclose being at a location from which a spouse could infer that the witness was visiting a lover.

The considerations presented above in support of the nondisclosure of DNA-related IFs merit consideration with regard to other kinds of IFs, and many of them apply straightforwardly to non-genetic IFs. Embracing a general policy of not disclosing them may help to prevent the identification effort from being co-opted to serve other social or

individual interests, for example, using information revealed about the circumstances of a person's death to tarnish the deceased's reputation for political gain or to fuel reprisals against those who appear responsible for the death. Implementing a policy of not revealing incidental information would prevent one family from learning such information (e.g., information contained in police files), while another family with an identified loved one does not. In a post-conflict context, for example, such different disclosures may raise suspicions that those conducting the identification effort are "taking sides" or engaging in differential treatment of victims and families. Even though the reason for the different disclosures is likely to be simply that no incidental information was discovered with regard to the second person whose remains were identified, it is advisable to avoid sparking such suspicion. Maintaining the public's confidence in the fairness and integrity of the identification effort, and avoiding imposition of risks on participants, generally argue in favor of a policy of nondisclosure of IFs of any kind.

Although we believe that many of the considerations that we outline above support a general policy of not disclosing incidental findings of any type, we recognize that when it comes to the full range of possible IFs it may be difficult to discern what is and is not incidental to the overarching social goals or specific mandate of a particular identification effort. Photographs documenting the circumstances surrounding the deceased's death or the condition of the body, for example, may be pertinent to criminal or civil proceedings, human rights investigations, transitional justice, or broader activities whose goals the identification effort serves. There may also be legitimate differences between the discovery of unexpected information about the missing person and the discovery or disclosure of private information about third parties. While family members may have a legitimate interest in knowing where their loved one died, for example, they may not have a legitimate interest in knowing that a witness to that death was engaged in an extramarital affair.

As with genetic IFs, it is important to disclose during the informed consent process the possibility of discovering non-genetic IFs. Development of a policy to manage these IFs avoids the need for investigators to make ad hoc decisions based on their judgment of the particular circumstances of individual cases. Implementation of a policy helps to ensure consistent management of findings and equitable treatment of participants. Articulating the policy during informed consent allows prospective participants to protect their interests by consenting or refusing to participate in light of the possibility that such IFs will (or will not) be disclosed.

## Conclusion

We have argued that prior to initiating an identification effort, it is important to develop policies to manage incidental findings, defined as information that is beyond the aim of the effort's mandate. Focusing specifically on IFs relating to kinship discrepancies, we have argued that the discovery of IFs should be minimized by scientific practices when such minimization can be reasonably undertaken, and a policy of nondisclosure of IFs should generally be adopted at the inception of identification efforts. A policy of nondisclosure is supported by the ethical desirability of establishing fair terms of participation for identification efforts that maximize equitable access to the personal and social benefits of participation and that minimize associated risks. Although reference sample donors must accept the unavoidable risk of IFs being discovered, the likelihood of such discovery should be minimized through careful choice of scientific practices, and the risks of harm associated with discovery should be minimized.

A policy of nondisclosure should be explained as part of the information imparted during the informed consent process and on consent forms. Adoption of a different policy—either to

disclose or publicize IFs, or to respond to individual requests for their disclosure—would need strong justification that rebuts the points made above in support of nondisclosure. It would then need to be explained to, and accepted by, participants during informed consent.

Similarly, during informed consent, the policies governing recording, storing, and securing the privacy of all findings, including IFs, must be explained, along with the risks of inadvertent breach of the privacy and security of such information. Further, the risks associated with any plans to make records public must be explained. Strong measures should be implemented to ensure the privacy and security of stored samples, raw data, and information resulting from analyses. Limitations of those involved in the identification effort to enforce those measures should also be explained. Prospective participants must be given a chance to consent to, or refuse, their participation in light of all of these disclosures.

## Acknowledgments

This work was made possible by Grant Number R01 HG005702 from the Ethical, Legal, and Social Implications Research Program of the U.S. National Institutes of Health's National Human Genome Research Institute (PI: Aronson). Its contents are solely the responsibility of the authors and do not necessarily represent the official views of NIH or NHGRI. We would like to thank the six anonymous practitioners who spoke to us about the challenge of incidental findings in the identification of the missing after conflict and disaster.

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